Self-care behaviour
in terms of compliance and delay
of patients with heart failure

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Contents

Chapter 1

Introduction

Introduction

Heart failure (HF) affects approximately 3% of the general population, with a prevalence of 10-20% in the elderly. The prevalence of HF is rising, because of older age and increased survival from ischemic and other cardiovascular diseases due to improved medical care. Despite these improvements, HF still has a poor prognosis with about 50% of patients are dead 4 years after diagnosis and 40% of patients admitted for HF are dead or readmitted within 1 year.[1]

The complex HF regimen consists of pharmacological and non-pharmacological treatment. According to the recent HF guidelines of the European Society of Cardiology[1] and the Heart Failure Society of America,[2] multiple medications should be prescribed at an optimal dose. Non-pharmacological treatment consists of lifestyle recommendations; the most important ones are sodium-restricted diet, fluid restriction, symptom monitoring by daily weighing and maintenance of physical activity. It is important that health care providers treat patients according to these guidelines.[3] Patients should be active partners with their health care providers in their own care; those who are actively involved in their own care and treatment and comply with the regimen have improved survival and decreased readmissions.[4,5] This underlines the importance of the patients' own active role by performing adequate self-care behaviour.

Self-care behaviour in HF

Adequate self-care behaviour related to HF can be defined as the actions that patients undertake to maintain healthy functioning, and well being. Self-care behaviour includes compliance with medication and lifestyle recommendations (e.g. diet, fluid restriction and exercise), symptom monitoring (e.g. daily weighing to assess fluid retention), self-management of symptoms, and care seeking in case of worsening symptoms (Figure 1).[6]

Compliance with medication and lifestyle changes

According to the World Health Organization (WHO), compliance (or adherence) can be defined as 'the extent to which a persons' behaviour (in terms of taking medication, following diet, or other lifestyle changes) coincides with agreed recommendations from a health care provider'.[7] Although non-compliance with the HF regimen is associated with adverse outcomes,[4,5] many HF patients do not take their medications as prescribed and do not follow the lifestyle recommendations; it is estimated that only 40-70% of the HF patients take their medication as prescribed.[8,9] Non-compliance with non-pharmacological

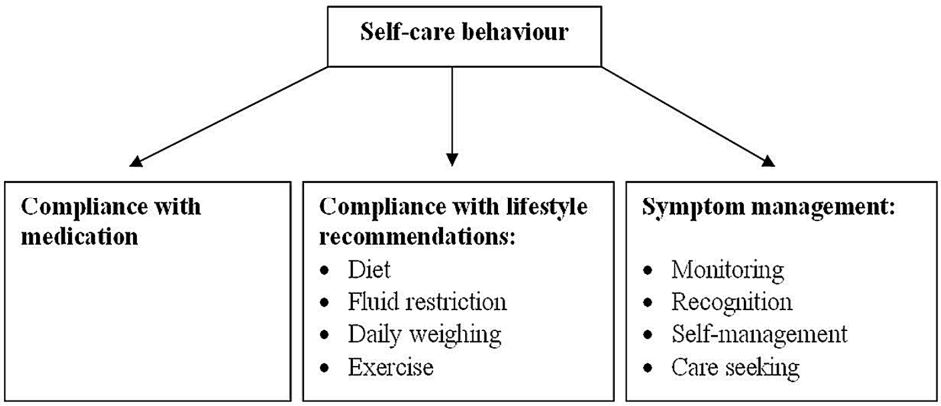

Figure 1. Components of HF-related self-care behaviour

treatment is also very common in HF patients; compliance with diet and fluid restriction is reported to range from 50-96% and 23-70% respectively.[9,10] Compliance with daily weighing ranged from 12-75% and compliance with exercise in most studies was around 50%.[9]

A wide variety of factors are found to be related to non-compliance; these factors can be divided into patient-related factors (e.g. age, gender), regimen-related factors (e.g. complexity), and health care provider-related factors (e.g. number of contacts with the health care provider).[9] One should be aware of the fact that patient-related factors should be differentiated into factors that can be changed or improved by education and counselling, such as knowledge and beliefs; and factors that cannot be changed but can be used to identify those patients at higher risk for non-compliance (e.g. age, gender). The presence of depressive symptoms is a patient-related factor that can affect the effectiveness of education and counselling,[11] and is also found to be related to inadequate self-care behaviour.[8,12]

Symptom management

Patients are recommended to actively monitor their symptoms. Early recognition of symptoms of HF is important, since they might be warning signs of further deterioration.[1] Many admissions could have been prevented if patients had sought medical care in an earlier stage of worsening symptoms.[13,14,15] However, long delay times are common in HF

patients, mostly because of the gradual pattern of worsening symptoms and, subsequently, the inability to recognize the seriousness of worsening symptoms.[16]

In general, delay reflects the time between worsening symptoms and the moment that a health care provider or the health care system is involved in the process of anticipation to these symptoms. The most commonly used definition of delay in the HF literature is *pre-hospital delay*, indicating the time between worsening symptoms and arrival at the hospital. A wide variety of delay times have been reported, varying from 12 hours to 1 week before patients were hospitalized.[13] A substantial part of this pre-hospital delay consists of *patient delay*, defined as the time from worsening symptoms to actually contacting a health care provider, and this definition reflects the delay time based on the patients' own decision.

Aims of the thesis

The importance of adequate self-care behaviour has been recognized in terms of clinical outcome. Patients should be aware of the fact that they should be actively involved in their own care by complying with the regimen and by adequately managing their HF symptoms. It is, therefore, a major challenge to identify those patients who are at an increased risk for inadequate self-care behaviour and to assess factors related to inadequate self-care behaviour. The body of knowledge on factors associated with self-care behaviour in terms of compliance and delay has been well established in the existing literature. However, the use of different measurements instruments and definitions of compliance in previous studies may have led to different reported compliance rates. Furthermore, most of the studies on compliance are cross-sectional or focused on compliance with one specific recommendation instead of the total package of the separate non-pharmacological recommendations. Little is known about long-term compliance with non-pharmacological treatment and its determinants. Considering delay after worsening HF symptoms, most studies were focussed on pre-hospital delay. Patient delay (time from worsening symptoms to actually contacting a health care provider) actually reflects the delay time based on the patients' own decision. To obtain more insight in the role of the patient in their own care and treatment in terms of self-care behaviour and in other factors related to self-care behaviour, the following aims of this thesis are formulated:

1) To assess compliance with medication and its associated factors
2) To assess which factors are associated with compliance with lifestyle recommendations

3) To assess long-term compliance with lifestyle recommendations and its associated factors
4) To assess which factors are associated with delay after worsening symptoms

To examine self-care behaviour and its associated variables in HF patients, several substudies in the Dutch Coordinating study evaluating Outcomes on Advising and Counselling in Heart failure (COACH),[17,18] a study designed to evaluate the effect of education and counseling by an HF nurse on clinical outcomes in HF patients, were conducted.

The first part of this thesis focuses on compliance with the HF regimen. Chapter 2 is specifically focussed on compliance with medication. In this chapter, differences between self-reported and objectively measured compliance by the Medication Event Monitoring System (MEMS) will be described. An evidence-based cutpoint has been used to define compliance, which not only reflects (non)compliance, but also identifies those with an increased risk of adverse outcomes. In chapter 3, objectively measured compliance with sodium-restricted diet and fluid restriction and its associated variables will be described. Compliance has been measured using a nutrition diary and individually prescribed sodium- and fluid restrictions have been used to differentiate between compliance and non-compliance. In chapter 4, long-term compliance with the non-pharmacological lifestyle recommendations (i.e. diet, fluid restriction, daily weighing and exercise) will be described. Additionally, factors associated with low compliance with these recommendations have been assessed. Chapter 5 is the final chapter on compliance and focuses specifically on exercise recommendations. In this chapter, the role of motivation and perceived control in compliance with these recommendations will be described and discussed.

The scope of the second part of this thesis is on delay after worsening HF symptoms. In chapter 6, the association between depressive symptoms and pre-hospital delay and its relation between consulting behaviour will be described. Chapter 7 focuses on the patients' own role in terms of delay by assessing the specific patient delay and its associated variables. This patient delay and its associated variables have been assessed in patients with and without a history of HF. The final chapter of this thesis will discuss the main results of the previous chapters. Based on these results, future perspectives and implications for clinical practice and further research will be discussed.

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Part I

Self-care behaviour: Compliance

Chapter 2

Self-reported versus ‘true’ adherence in heart failure patients: a study using the Medication Event Monitoring System

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Abstract

Background

Adherence to (non)pharmacological treatment is important in heart failure (HF) patients, since it leads to better clinical outcome. Although self-reported and objectively measured medication adherence in HF patients have been compared in previous studies, none of these studies have used an evidence-based cutpoint to differentiate between adherence and non-adherence.

Methods

In 37 HF patients (mean age 68 ± 10 years, 27% female, 40% NYHA functional class III-IV), medication (ACEi/ARB) adherence was objectively measured using the Medication Event Monitoring System (MEMS). Adherence to and importance of taking medication was also assessed by self-report using the Revised HF Compliance Questionnaire.

Results

All patients reported that adherence was (highly) important to them and that they 'always' took their medication as prescribed (i.e. 100% adherence). However, when measured by the MEMS, only 76% of all patients were adherent. Non-adherent patients more often had a complex medication regimen (78% vs. 21%, P <.01), more often depressive symptoms (75% vs. 29%, P =.04) and a shorter history of HF (8 vs. 41 months, P =.04), compared with adherent patients.

Conclusions

Medication adherence measured by the MEMS was remarkably lower than self-reported adherence. Given the evidence of its importance, further efforts are needed to improve adherence to the pharmacological regimen in HF patients.

Introduction

Adherence to the pharmacological regimen and non-pharmacological lifestyle changes is an important issue in heart failure (HF). Adherence, defined as 'the extent to which the behaviour corresponds with agreed recommendations from a health care provider[1]', leads to better outcome in HF patients.[2-4] As a result of improvement in treatment in the last decade, the HF regimen is becoming increasingly complicated. According to international guidelines, multiple medication should be prescribed at an optimal dose,[5] leading to a reduction in hospitalisations.[6] However, drugs do not work in patients who do not take them. Medication adherence in HF patients is not optimal, with rates ranging from 10% to 96%,[7,8] depending on measurement and definition of adherence. Important factors associated with adherence are socioeconomic status, symptom severity, depression, complexity and costs of the regimen, perceived benefits and side effects.[8,9]

The importance of medication adherence has been recognised and is therefore well established in the current literature. However, it is difficult to come to a general conclusion about medication adherence due to methodological issues in previous studies.[8] Firstly, adherence in previous studies was measured using self-report and a variety of more objective measures, such as pharmacy refill and the medication event monitoring system (MEMS). Self-report is a widely accepted and applied method to assess medication adherence, however, this may be less reliable to fully reflect true adherence. Secondly, in most studies on medication adherence, the rationale of choosing a cutpoint to define adherence in order to differentiate between adherence and non-adherence was either not given or arbitrarily chosen. This cutpoint differed per study, which may also have resulted in different reported adherence rates. Given the importance of adherence, using an evidence-based cutpoint seems to be a crucial aspect in studying adherence with respect to clinical relevance. An evidence-based cutpoint not only reflects (non)adherence, but also identifies those patients with an increased risk of adverse outcomes.

Although medication adherence objectively measured by MEMS registration has been compared with self-reported adherence in previous studies,[3,10] none of these studies have used an evidence-based cutpoint to differentiate between objectively measured adherence and non-adherence. Therefore, the aims of this study were to describe differences in self-reported and objectively measured medication adherence by the MEMS based on an evidence-based cutpoint in a HF population and to assess differences between adherent and non-adherent patients.

Methods

A subsample of 37 patients participating in the COACH (Coordinating study evaluating Outcomes of Advising and Counselling in Heart failure) study[11,12] was analysed. The main objective of COACH was to evaluate the effect of a moderate or intense nurse-led disease management program on clinical outcome in HF patients. At baseline, patients were randomly assigned to a control (care as usual) or an intervention group (basic or intensive support) and were followed during a fixed, 18-month period after discharge. Along with the routine management by the cardiologist, patients in both intervention groups received additional care from an HF nurse which consisted of comprehensive education and counselling about HF and the regimen at baseline and during follow-up, according to protocol. The study complied with the Declaration of Helsinki and the Medical Ethics Committee granted approval for the protocol.

For this substudy, longitudinal data on medication adherence collected during COACH were used. Adherence to ACE inhibitors (ACEi) or angiotensin receptor blockers (ARB) was measured using the Medication Event Monitoring System (MEMS; AARDEX-USA, Ltd., Union City, CA). Exclusion criteria were the use of a medication supply box, preparation of medication by others than the patient, end-stage HF or another terminal disease. At either 1, 6 or 12 months after discharge at the corresponding assessments of COACH, patients were approached by a research assistant to ask them to participate in this substudy.

Measurement of adherence: the MEMS

Adherence to ACEi/ARB was objectively measured using the MEMS device. The MEMS is an electronic monitoring system with a computer chip embedded in the cap of the bottle, recording each time the cap is removed. Real-time data were collected on the device and were transferred to a computer at the end of the monitor period. The MEMS bottles were filled by the patients' local pharmacy and patients were informed about the monitoring procedure, the time of refilling and the number of provided tablets. Patients were instructed to open the MEMS bottle only when they actually took their medication and to write down all other openings (i.e. refilling or by accident). These additional events were removed from the MEMS data prior to analysis.

The MEMS registered the percentage of the prescribed doses taken during the monitored period ('taking adherence') and the percentage of days on which the patient took the accurate, prescribed doses of medication ('dosing adherence'). Wu and colleagues

found that event-free survival was significantly better when the prescribed number of doses taken or the percentage of days the correct number of doses was taken was ≥88%.[13] Therefore, also in this study, patients were considered to be adherent when their taking or dosing adherence was ≥88%.

Measurement of adherence: self-report

Self-reported adherence was measured with the Revised HF Compliance Scale[14] on a five-point scale (1 = 'never'; 5 = 'always'). Patients were considered to be 'adherent' when they reported that they had taken their medication 'always' or 'mostly' during the last week, which is confirmative with other studies.[2,14,15] Importance of and difficulty with taking medication was assessed on a similar five-point scale. Data on self-reported adherence collected at the same moment (i.e. 1, 6 or 12 months after discharge) that monitoring with the MEMS was started were used for analyses.

Other study measurements

At baseline and 1, 6, and 12 months after discharge, knowledge on HF and the regimen was measured with the Dutch HF Knowledge Scale.[16] The Centre for Epidemiological Studies Depression Scale (CES-D) was used to measure the presence of depressive symptoms (CES-D ≥16)[17] and was completed at baseline and 12 and 18 months after discharge. Data on HF knowledge and depressive symptoms collected most closely to the start of registration by MEMS were used for analysis. At baseline, clinical variables and demographics were collected from the patients' medical record and by interview.

Statistical analysis

Descriptive statistics were used to characterise the study population and to examine medication adherence. Differences between adherent and non-adherent patients were tested with Chi-square tests or Fisher's exact tests for dichotomous variables and Mann-Whitney tests for continuous variables. A *P*-value <.05 was considered as statistically significant. All analyses were performed with SPSS 16.0 (SPSS Inc, Chicago, IL).

Results

A total of 263 of the patients participating in COACH were eligible to participate in the substudy and 226 of these patients did not meet the inclusion criteria: 137 patients used a medication supply box, 37 patients were not prescribed an ACEi or ARB, and 24 patients

Table 1. Characteristics of the study population and differences between adherent and non-adherent patients based on the MEMS (n = 37)

	All patients (n = 37)	Adherent patients (n = 28)	Non-adherent patients (n = 9)	*P*-value
Demographics				
Age (years), mean ± SD	68 ± 10	69 ± 9	63 ± 10	.10
Female gender % (n)	27% (10)	29% (8)	22% (2)	1.00
Living alone, % (n)	30% (11)	25% (7)	44% (4)	.40
High educational level, % (n)	19% (7)	25% (7)	0% (0)	.16
Clinical variables				
LVEF (%), mean ± SD	33 ± 13	34 ± 14	29 ± 7	.40
NYHA class (discharge) III-IV, % (n)	40% (15)	43% (12)	33% (3)	.70
Length of HF (months), mean ± SD	33 ± 54	41 ± 59	8 ± 22	.04
Previous HF admission, % (n)	19% (7)	25% (7)	0% (0)	.16
Depressive symptoms, % (n)	39% (14)	29% (8)	75% (6)	.04
Ischemic HF, % (n)	35% (13)	36% (10)	33% (3)	1.00
Comorbidity				
Diabetes, % (n)	16% (6)	11% (3)	33% (3)	.14
COPD, % (n)	8% (3)	7% (2)	11% (1)	1.00
Hypertension, % (n)	38% (14)	43% (12)	22% (2)	.43
Medication				
Dosage >1 time a day, % (n)	35% (13)	21% (6)	78% (7)	<.01
Monitored medication:				.31
- ACEi, % (n)	86% (14)	82% (23)	100% (9)	
- ARB, % (n)	14% (5)	18% (5)		
Days monitored with MEMS, mean ± SD	114 ± 26	117 ± 25	107 ± 30	.40
Total number of medications, mean ± SD	6.6 ± 2.1	6.5 ± 2.3	6.7 ± 1.7	.76
HF knowledge				
Total score, mean ± SD	13.0 ± 1.9	13.3 ± 1.2	11.9 ± 3.1	.12

ACEi *angiotensin converting enzyme-inhibitor,* ARB *angiotensin receptor blocker,* COPD *chronic obstructive pulmonary disease,* HF *heart failure,* LVEF *left ventricular ejection fraction,* MEMS *medication event monitoring system,* NYHA *New York Heart Association.*

refused to participate. Other reasons for exclusion were: discharge to a nursing home (n = 9), withdrawal from COACH (n = 8), presence of end-stage HF or another terminal illness

(n = 3) or other reasons (n = 8). The mean age of the study population (n = 37) was 68 ± 10 years, 27% were female and 40% were in New York Heart Association (NYHA) functional class III-IV at discharge, with a mean left ventricular ejection fraction (LVEF) of 33 ± 13% (Table 1). Patients were monitored by MEMS for a mean duration of 114 days (range 54-155 days). Thirteen patients were enrolled in the substudy 1 month after discharge; 20 patients at 6 months, and 4 patients started with monitoring at 12 months during follow-up. Moment of enrolment and total monitored days was not associated with adherence.

Adherence: self-report versus the MEMS

All 37 patients reported that they 'always' took their medication as prescribed (i.e. 100% adherence). They also reported that taking medication was '(highly) important' to them. None of the patients reported problems with taking medication.

When adherence was measured using the MEMS, 76% of all patients were adherent to their medication, since their taking or dosing adherence was ≥88%. In all patients, the mean 'taking compliance' was 94 ± 17%, indicating that 94% of the prescribed medication was taken by the patients, although it was still possible that patients did not take the correct dose every day. The mean 'dosing adherence' was 90 ± 24%, indicating that in 90% of all monitored days, the prescribed daily dose of the medication was taken. Adherence to ACEi was monitored in 86% of the study population, adherence to ARB in 14%. Figure 1a presents MEMS data of a non-adherent patient who had to take his medication twice a day. This patient took his medication at many different time points, with a wide range of intervals between the doses taken (0.5-47.8 h). In contrast, Figure 1b presents data of an adherent patient (also with a 'twice a day regimen'), who was more structured in taking his medication.

Non-adherent patients were more often prescribed an ACEi/ARB 2-3 times a day instead of once a day, compared with adherent patients (78% vs. 21%, P <.01). Non-adherent patients also reported more depressive symptoms (75% vs. 29%, P =.04) and had a shorter history of HF (8 vs. 41 months, P =.04). Although not statistically significant, none of the non-adherent patients had a history of a previous admission for HF, whereas a quarter of the adherent patients had such a history. No differences in knowledge were found between adherent and non-adherent patients (Table 1). Of all patients, 13 were in the 'care as usual' group during follow-up; 24 patients were in one of the intervention groups ('basic/intensive support'). No differences in adherence were found between the different groups.

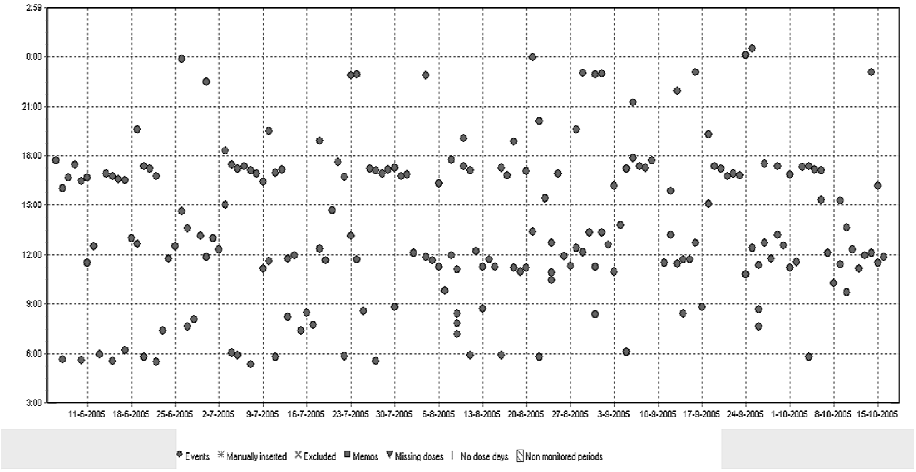

Figure 1a. *MEMS data of a patient who was prescribed lisinopril 10 mg, twice a day. Every dot on the diagram indicates an opening of the MEMS bottle. He was monitored for 134 days, so he had to take 268 tablets, but he took 198 tablets (taking adherence 73.8%). Dosing adherence was 43.4%, indicating that he took the correct number of tablets on 43.4% of the monitored days.*

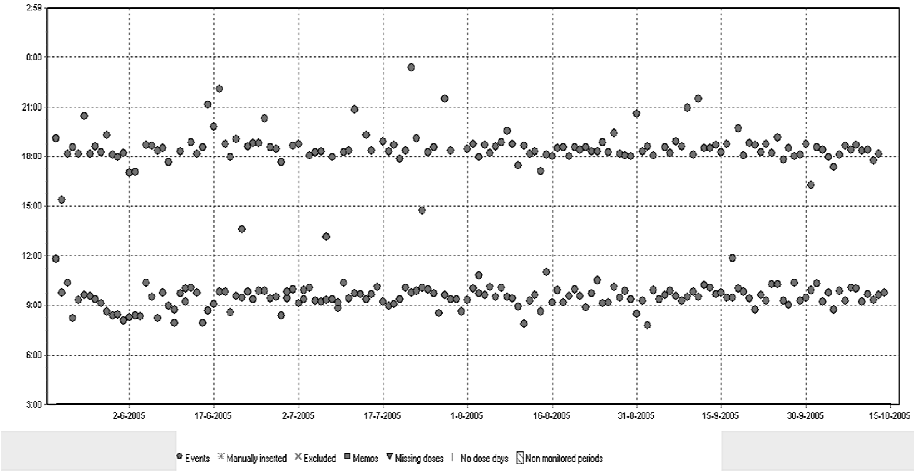

Figure 1b. *Data of a patient who was prescribed enalapril 5 mg, twice a day and was monitored for 149 days. This patient had a taking adherence of 97.9% and a dosing adherence of 93.3%.*

Discussion

This study compared self-report with objectively measured medication adherence using an evidence-based cutpoint in the same study population. The main result of this study is that medication adherence objectively measured by MEMS was remarkably lower than self-reported adherence. All patients reported 100% adherence, they considered taking medication to be (very) important, and they perceived no difficulties with taking medication. However, 1 out of 4 patients did not actually take their medication as prescribed. Moreover, these patients were not only non-adherent, but also had an increased risk for adverse outcomes, since adherence was defined using an evidence-based cutpoint (≥88%). Two possible explanations may underlie the differences between self-reported and objectively measured adherence. Firstly, patients who reported to be adherent, but appeared to be non-adherent when measured objectively, may be convinced that they actually took their medication as prescribed, since forgetfulness is a prominent barrier to adherence.[8] Secondly, patients may not want to admit that they were non-adherent, and therefore reported to be adherent. Although it is still possible that patients did open the cap but did not actually take their medication, the MEMS may be less vulnerable to social desirability and especially recall problems than self-report,[18] since it obtains real-time data.

Another aim of the study was to assess differences between adherent and non-adherent patients, based on an evidence-based cutpoint. We confirmed that non-adherent patients were more often prescribed a complex medication regimen (2-3 times a day medication vs. once a day).[19] Although patients were also prescribed medications other than ACEi/ARB during the monitoring period, it is stated that monitoring one medication accurately reflects adherence with other medication.[3] The total number of other medications did not affect adherence. Therefore, regarding complexity of the regimen, we conclude that the amount of dosages a day (2-3 times vs. once), but not the total number of prescribed medication, affects adherence in HF patients.

Non-adherent patients also had a shorter history of HF reflecting less routine in taking medication. A history of HF can be an important aspect in adequate self-care.[20] In line with this, it was found that none of the non-adherent patients and 25% (n = 7) of the adherent patients had a previous admission for HF. This is confirmative with other studies[21,22] and, although not statistically significant, can be clinically meaningful in terms of learning about the seriousness of HF with respect to medication adherence. A previous HF admission may result in more vigilance in taking medication as prescribed. Furthermore, non-adherent patients more often had depressive symptoms, possibly due to

impaired cognition, feelings of hopelessness or lack of optimism.[23,24] Other studies also showed that there is an association between depressive symptoms, adherence and outcome.[15,25,26]

Although we found that self-report does not reflect the actual adherence and more objective measurement instruments are superior, there is some role for assessing adherence using self-report by researchers and clinicians. When patients report themselves to be non-adherent, this is actually often the case, since it was found that self-reported non-adherence corresponds with objectively measured non-adherence.[10] However, HF patients commonly overestimate their medication adherence, and therefore it is suggested that self-report is able to detect non-adherence, but seems to be less sensitive for detecting adherence. Therefore, self-reported adherence should be interpreted with caution in clinical practice and studies.[3]

This study showed that medication adherence is still a problem in HF patients, and that patients are not always as adherent as they say. It also underlines the difficulty in really getting a good assessment of adherence. Health care providers should be aware of this when discussing adherence with their patients. Possible barriers to medication intake as prescribed (adverse side effects or practical problems, as a result of intake of diuretics) should be addressed and health care providers should help patients to manage these barriers in order to increase adherence. In case of forgetfulness, patients should be provided with reminders or conditions that make it less likely to forget medication (such as a medication supply box, or assistance by homecare or pharmacists). Changing the patients' prescription to a 'once a day regimen' is an intervention that could easily be implemented in daily practice and will also help patients to manage their complicated HF regimen. Additionally, health care providers should stress the importance of adherence by focusing on possible consequences of not taking medication at the prescribed dose.

Our study has some limitations. The first one is the small sample size and, therefore, only univariate analyses were performed. Another limitation is the inability to generalise the results to the whole HF population, since patients using a medication supply box were excluded.

Conclusion

Medication adherence objectively measured by MEMS was remarkably lower than self-reported adherence, indicating that self-report seems to be prone to overestimating the patients' true adherence. All patients in the study reported to be adherent, but 1 out of 4 patients were actually non-adherent and, therefore, were at an increased risk for adverse

outcomes. Given the evidence of its importance, further efforts are needed to improve medication adherence. With respect to clinical relevance, further research should focus on identifying characteristics of patients who are non-adherent by taking less than 88% of their prescribed medication. This can help health care providers to focus on these patients and to implement education and counselling targeted at improving adherence and, therefore, reducing risk for adverse outcomes.

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Chapter 3

The body of knowledge on compliance in heart failure patients: we are not there yet

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Abstract

Background

Non-compliance with diet and fluid restriction is a problem in patients with heart failure (HF). In recent studies, a relationship between compliance with sodium and fluid restriction and knowledge and beliefs regarding compliance was found. In these studies, however, compliance was primarily measured by interview or questionnaire.

Objectives

To examine the relationship between compliance with sodium and fluid restriction measured with a nutrition diary and knowledge, beliefs, and other relevant variables in HF patients.

Methods

Eighty-four HF patients completed a nutrition diary for 3 days. Patients also completed questionnaires on knowledge, beliefs regarding compliance, and depressive symptoms. Differences in relevant variables between compliant and non-compliant patients were assessed.

Results

Compliance with sodium and fluid restriction was 79% and 72%. Although not statistically significant, a higher percentage of patients were compliant with the less stringent restrictions compared with the more stringent restrictions, and in addition, more non-compliant patients perceived difficulty following the regimen compared with their compliant counterparts. In contrast with other studies, no significant differences in knowledge, beliefs, and relevant demographic and clinical variables were found between compliant and non-compliant patients.

Conclusion

Perceived difficulty and the amount of the prescribed restriction seem to be relevant concepts that play a role in compliance with sodium and fluid restriction in HF and need to be explored in future research.

Introduction

According to recent heart failure (HF) guidelines, adjustment of sodium and fluid intake is an important nonpharmacological recommendation for patients with symptomatic HF.[1,2] Non-compliance with these recommendations is associated with clinical instability and an increased risk of HF readmission or death,[3] mostly due to volume overload.[4,5] According to the World Health Organization, compliance can be defined as 'the extent to which the behavior corresponds with agreed recommendations from a health care provider'.[6] From a systematic literature review, it is known that many HF patients are not complying with these recommendations; the lowest reported compliance rates regarding sodium and fluid restriction were 43% and 23%.[7]

According to the Health Belief Model, one of the theories that can explain compliance, individuals will take action if they believe that anticipated barriers, including psychological costs, of specific health behavior (compliance) are outweighed by benefits.[8] Benefits refer to the perceived benefits of adopting the recommended health behavior (e.g. personal beliefs about the effectiveness of the behavior). Perceived barriers are the potential negative consequences that may result from taking particular actions.[9] Negative beliefs may make it more difficult to comply with the lifestyle recommendations, and if patients perceive more difficulty with the health behaviour, compliance will decrease.[10] Based on existing literature on compliance, one might expect that compliant patients have more knowledge on HF, perceive more benefits of and fewer barriers to compliance, and perceive less difficulty following the regimen compared with non-compliant patients.[11-14] Furthermore, associations between compliance and age,[10] gender,[15] and depressive symptoms[11,16] were found. Current data on compliance with sodium and fluid restriction are mainly obtained by patient interviews and self-reported questionnaires. A limitation of these measurement instruments is that they can lead to social desirable answers and recall problems; in addition, measurement of compliance with sodium restriction can also lead to bias when patients do not have enough knowledge on the amount of sodium in their food.[17] Another limitation of prior studies is that sodium and fluid intake were primarily compared with a fixed, standard restriction instead of tailored restrictions prescribed to the individual patient. Therefore, the aims of the present study were as follows: (1) to examine compliance rates based on nutrition diary data in HF patients; (2) to assess differences in knowledge and beliefs between compliant and non-compliant patients; and (3) to assess differences in other relevant variables between compliant and non-compliant patients.

Methods

Between February 2005 and June 2006, a subsample of 84 HF patients participating in the COACH study (**C**oordinating study evaluating **O**utcomes of **A**dvising and **C**ounseling in **H**eart failure) was included in the present study. COACH was a randomized, multi-center, controlled study in which 1023 HF patients were included.[18,19] Inclusion criteria were admission because of HF, evidence of structural underlying heart diseases, and being at least 18 years of age. Exclusion criteria were participation in another study, a planned or recent invasive cardiac intervention, or inability to complete data collection formats. The main objective was to evaluate the effect of education and counseling by a HF nurse on clinical outcome. Patients were randomised to either a control group ('care as usual', routine management by the cardiologist) or to one of the intervention groups ('basic' or 'intensive support'). Patients in both intervention groups received, along with the routine management by the cardiologist, additional care from a HF nurse, which consisted of comprehensive education and counseling about HF and the HF regimen. The study complied with the Declaration of Helsinki. The medical ethics committee granted approval for the protocol, and all patients provided written informed consent. Patients were recruited and examined during a fixed period of 18 months after discharge from the hospital. In the present study, compliance, knowledge, beliefs, and depressive symptoms were measured 12 months after discharge.

All patients who were still in the in COACH study between February 2005 and June 2006 at 12 months during follow up received a nutrition diary along with the 12-month questionnaires. Patients were asked to record their complete daily food and fluid intake for 3 days; 2 days throughout week and 1 day during the weekend. Patients who completed a nutrition diary did not differ in age, gender, and left ventricular ejection fraction (LVEF), compared with the patients from the COACH study who did not participate in the substudy.

Clinical and demographic variables

During admission of the index hospitalization (baseline), clinical variables were assessed from the patients' medical record. Demographic variables were collected at baseline and 12 months after discharge using interviews by an independent data collector. Depressive symptoms were measured with the Center for Epidemiological Studies Depression Scale (CES-D).[20] This scale consists of 20 items and measures the presence of depressive feelings and behaviors. A score of 16 or higher is an indication for depressive symptoms.

Compliance

Compliance with sodium and fluid restriction was measured with a nutrition diary. The diary was validated in a pilot study with a high correlation between reported sodium intake and urine sodium excretion (r = .72; P <.05).[17] All recorded nutrition intakes were computed into total amounts of sodium (in milligrams) and fluid (in milliliters) for each day by an experienced dietitian using a validated software (ZIS Nutrition; HISCOM, iSOFT Nederland B.V., Leiden, the Netherlands). Regarding fluid intake, patients were instructed to define the volumes of their tableware in milliliters. Otherwise, standard volumes were used (1 cup of coffee/ tea = 125 mL, 1 glass/ cup of soup/ small bowl = 150 mL). In case of a daily intake of more than 2 pieces of fruit, an amount of 100 mL has been added for each extra piece of fruit.

To determine whether or not patients were compliant with their restriction, the mean daily fluid and sodium intakes obtained from the diary were compared with the prescribed restriction at baseline. Because not all patients had actually weighed their food but described the general amounts of food (e.g. '1 steak' instead of 'a 2-oz steak') or did not measure their fluid intake, estimations of the amount of mean daily intakes were made by the dietitian. To correct for this, patients were defined as non-compliant if their mean daily intake exceeded their prescribed restriction with more than 10%. In general, HF patients are recommended to restrict their daily sodium and fluid intake with at least 3000 mg and 2500 mL. For patients in New York Heart Association (NYHA) class III-IV a more stringent restriction (2000 mg and 1500-2000 mL) is recommended, according to the Dutch HF-guidelines.[21] Patients with no prescribed restriction at baseline were defined as non-compliant if their intakes exceeded the least stringent restriction with more than 10%.

Heart failure knowledge

Knowledge was measured with the Dutch HF Knowledge Scale, which consists of 15 multiple-choice items (range, 0-15). This scale is a reliable and valid instrument to measure knowledge on HF in general, symptom recognition, and HF treatment.[22] One item was specifically related to sodium restriction and 2 items were related to fluid restriction. Patients were classified as having a high or low level of knowledge based on the median score.

Heart failure beliefs

Beliefs about compliance with a sodium-restricted diet were measured with one of the subscales of the Heart Failure Belief Scale.[23] This subscale measures 7 benefits of and 5

barriers to compliance with sodium restriction. An example of a benefit-related item is 'eating a low salt diet will keep me healthy'; one of the assessed barriers was 'food does not taste good on the low salt diet.' Items can be rated on a 5-point scale ranging from 1 (strongly disagree) to 5 (strongly agree). The belief scale is a reliable and valid instrument to measure beliefs of HF patients.[23] Beliefs about compliance with fluid restriction were not assessed.

Importance of and difficulty with the regimen

The subscales sodium restriction and fluid restriction of the Revised Heart Failure Compliance scale were used to assess the level of importance of and difficulty with compliant behavior regarding sodium and fluid restriction.[24] Patients were asked how important it was for them to follow a sodium and fluid restriction on a 5-point scale ranging from 1 (not at all important) to 5 (highly important). Scores were computed into 2 categories to differentiate between patients who found it 'not at all important' or 'a little important' and patients who found it 'important', 'very important', or 'highly important'. Patients also reported whether they perceived the restriction as difficult and what kind of problems they perceived.

Statistical analysis

Descriptive statistics were used to characterize the study population and to examine the level of importance of and the reasons for difficulty following prescribed restriction. Differences between compliant and non-compliant patients were tested with χ^2 tests or Fisher exact tests for dichotomous variables and Mann-Whitney *U* tests for continuous variables. $P < .05$ (2-tailed) was considered as statistically significant. All analyses were performed with SPSS 16.0 (SPSS Inc, Chicago, Illinois).

Results

Characteristics of the study population

The mean age of the study population was 70 years (range, 38-87), 32% of all patients were female, and 61% were of NYHA class II. No significant differences were found between NYHA class at discharge and NYHA class at 12 months.The mean length of HF symptoms was 2.3 years (range, 0-22.3), and the mean LVEF was 33 ± 15%. In total, 21% of all patients had depressive symptoms at 12 months (Table 1).

Table 1. Characteristics of the study population (n = 84)	
Demographics	
Age (years), mean ± SD	70 ± 11
Female gender, % (n)	32% (27)
Living with a partner, % (n)	64% (51)
High educational level, % (n)	13% (11)
Clinical characteristics	
Length of HF symptoms (years), mean ± SD	2.3 ± 4.6
LVEF (%), mean ± SD	33 ± 15
LVEF ≤40%, % (n)	79% (60)
Previous HF admissions ≥1, % (n)	29% (24)
Readmission during follow-up ≥ 1, % (n)	18% (15)
Depressive symptoms (CES-D ≥16), % (n)	21% (17)
NYHA functional class (at discharge), % (n)	
- II	61% (50)
- III	38% (31)
- IV	1% (1)
Etiology of HF	
CAD, % (n)	30% (25)
Hypertension, % (n)	17% (14)
Cardiomyopathy, % (n)	33% (28)
Other, % (n)	20% (17)
Comorbidities	
Diabetes, % (n)	29% (24)
Stroke, % (n)	10% (8)
Hypertension, % (n)	46% (39)
COPD, % (n)	31% (26)
Medication at discharge	
Diuretics, % (n)	95% (80)
ACE-Inhibitors, % (n)	74% (62)
ARBs, % (n)	10% (8)
β-Blockers, % (n)	66% (55)

ACE *angiotensin-converting enzyme;* ARB *angiotensin receptor blockers;* CAD *coronary artery disease;* CES-D *Center for Epidemiological Studies Depression Scale;* COPD *chronic obstructive pulmonary disease;* HF *heart failure;* LVEF *left ventricular ejection fraction;* NYHA *New York Heart Association.*

In the sample of the present substudy, 26% of the patients were in the 'care as usual' group and 74% received basic or intensive support during follow-up of the COACH study. Because no significant differences in demographics, clinical or other relevant variables,

such as knowledge, beliefs, and compliance, were found between the basic- and the intensive intervention group, these groups were pooled together as 1 intervention group. Furthermore, no significant differences were found between patients in the control or intervention groups in demographics or clinical variables.

Compliance

Of all patients, 61% (n = 51) were compliant with both fluid and sodium restriction, whereas 11% (n = 9) were non-compliant with both restrictions. Furthermore, 17% (n = 14) were compliant with only their sodium restriction and were non-compliant with their fluid restriction; 11% (n = 9) were compliant with only their fluid restriction and non-compliant with their sodium restriction. In summary, 39% of all patients were non-compliant with 1 of the 2 prescribed restrictions. No significant differences in compliance were found between patients in the control group and those in the intervention group.

Sodium

The mean daily sodium intake was 2050 mg, and 79% of all patients (n = 66) were compliant with their sodium restriction (Table 2). At baseline, 42 patients were prescribed a restriction of 2000 mg; 69% of these patients (n = 29) were compliant with this restriction. Of the 34 patients who were prescribed a restriction of 3000 mg, 85% (n = 29) were compliant (Table 3). Although not statistically significant, patients with a restriction of 3000 mg were more likely to be compliant compared with patients with a restriction of 2000 mg (*P* =.11). There were 8 patients without a prescribed sodium restriction. They had a mean sodium intake of 1684 mg (range, 941-3096 mg) and were considered as compliant.

Table 2. Sodium and fluid intake in compliant and non-compliant patients

	Sodium intake (mg) (n = 84)		**Fluid intake (mL) (n = 83)**	
	Compliant	**Non-compliant**	**Compliant**	**Non-compliant**
Total, % (n)	79% (66)	21% (18)	72% (60)	28% (23)
Mean ± SD	1786 ± 563	3019 ± 639	1399 ± 332	2425 ± 838
Median	1818	2903	1387	2210
Range	617-3219	2243-4331	565-2432	1617-5108

Table 3. Compliance with prescribed sodium restrictions

	2000 mg (n = 42)		3000 mg (n = 34)	
	Compliant	**Non-compliant**	**Compliant**	**Non-compliant**
Total, % (n)	69% (29)	31% (13)	85% (29)	15% (5)
Mean ± SD	1632 ± 402	2733 ± 474	1968 ± 612	3762 ± 329
Median	1559	2604	1866	3676
Range	617-2155	2243-3977	906-3219	3488-4331

Fluid

The mean daily fluid intake was 1683 mL, and 72% of all patients (n = 60) were compliant with their fluid restriction (Table 2). In total, 52 patients were prescribed a restriction of 1500mL or less; 26 patients were prescribed a restriction between 1500 and 2000 mL. Although not statistically significant (*P* =.20), a higher percentage of patients were compliant with a restriction of 1500 to 2000mL (81%, n = 21) compared with a more stringent restriction of 1500 mL or less (65%, n = 34) (Table 4). The mean daily fluid intake of the 6 patients without a prescribed restriction was 1799 mL (range, 958-2432 mL). All of these patients were considered compliant because their intake was less than 2500 mL.

Table 4. Compliance with prescribed fluid restrictions

	≤1500 mL (n = 52)		1500-2000 mL (n = 26)	
	Compliant	**Non-compliant**	**Compliant**	**Non-compliant**
Total, % (n)	65% (34)	35% (18)	81% (21)	19% (5)
Mean ± SD	1289 ± 238	2288 ± 869	1482 ± 314	2917 ± 517
Median	1343	2083	1457	2817
Range	565-1628	1617-5108	983-2060	2383-3750

Knowledge, beliefs, and compliance

Sodium

The mean score on knowledge was 12.7 for compliant patients and 12.3 for non-compliant patients (*P* =.58). Of the compliant patients, 35% (n = 23) had a low score (≤12) on knowledge, whereas 44% of the non-compliant patients (n = 8) had a low score on knowledge (*P* =.58). No significant differences were found in the scores on the individual

sodium restriction-related item of the knowledge scale between compliant and non-compliant patients. Furthermore, no significant differences were found in benefits of and barriers to a sodium-restricted diet between compliant and non-compliant patients, neither in the total scores nor in the scores on the individual items (Table 5).

Fluid

Compliant patients had a slightly higher mean score on knowledge compared with non-compliant patients (12.9 vs. 12.3; *P* =.16). No significant differences were found in the scores on the individual fluid restriction-related items of the knowledge scale between compliant and non-compliant patients. Of the compliant patients, 32% (n = 19) had a low score (≤12) on knowledge. In total, 50% (n = 11) had a low score on knowledge (*P* =.20) (Table 5).

Table 5. Scores on knowledge and beliefs regarding sodium and fluid restrictions

	Compliant	**Non-compliant**	**Theoretical range**	***P*-Value**
Sodium restriction				
Knowledge, mean ± SD	12.7 ± 1.5	12.3 ± 2.1	0-15	.58
Knowledge ≤12, % (n)	35% (23)	44% (8)		.58
Benefits-diet, mean ± SD	24.5 ± 2.9	24.8 ± 1.5	7-35	.55
Barriers-diet, mean ± SD	11.8 ± 3.4	12.6 ± 3.4	5-25	.48
Fluid restriction				
Knowledge, mean ± SD	12.9 ± 1.5	12.3 ± 1.7	0-15	.16
Knowledge ≤12, % (n)	32% (19)	50% (11)		.20

Patient characteristics and compliance

No significant differences in demographic variables were found between compliant and non-compliant patients. However, patients who were compliant with their sodium restriction slightly more often lived with a partner compared with non-compliant patients (68% vs. 50%; *P* =.18). Furthermore, although not statistically significant, compliant

patients had a shorter length of HF symptoms compared with non-compliant patients (2.0 vs. 3.7 years; *P* =.32). For compliance with fluid restriction, a similar result was found; compliant patients had a shorter length of HF-symptoms compared with non-compliant patients (2.0 years vs. 3.3 years; *P* =.10). No significant differences in depressive symptoms were found between compliant and non-compliant patients.

Importance of and difficulty following the regimen

Both compliant and non-compliant patients found it very or highly important to follow a low-salt diet (92% and 89%). However, non-compliant patients were more likely to find it difficult to comply with sodium restriction compared with compliant patients (33% vs. 17%; *P* =.18). A higher percentage of non-compliant patients (17%) reported 'practical problems' with the sodium restriction compared to compliant patients (3%) (*P* =.06). Lack of taste was the most reported problem by all patients.

Similar results were found for fluid restriction; both compliant and non-compliant patients found it very or highly important to follow a fluid restriction (97% and 95%). Although not statistically significant, non-compliant patients were more likely to perceive fluid restriction as difficult compared with compliant patients (32% vs. 17%; *P* =.23). The most reported problem with fluid restriction was thirst by both compliant and non-compliant patients (13% and 22%).

Discussion

Although the body of knowledge on determinants of compliance in HF patients is growing, the main finding of this study underlines that we need to consider additional factors, then the traditional determinants such as knowledge, beliefs, and demographic variables. Compliance with dietary sodium and fluid restriction was measured more accurately than in several other studies because, first, we used a nutrition diary, and second, we used personalized prescribed restriction to assess compliance.

In total, 11% were non-compliant with both restrictions, and 21% and 28% did not comply with their personalized advice on sodium and fluid restriction. In other words, 1 out of 5 of our patients does not follow one of the advices, and 1 out of 10 does not follow either, irrespective of additional education. Although measured differently, similar compliance rates were found in other studies,[11,12,24,25] but also lower percentages of 50% compliance with sodium restriction[26] and 33% compliance with fluid restriction[27] were reported. In our study, we found that a higher percentage of patients were compliant with

the less stringent restrictions, compared with the more stringent restrictions. However, these differences did not reach statistical significance.

From earlier studies, we did expect that compliant patients would have a higher level of knowledge and report more benefits of and fewer barriers to compliance with the regimen, compared with those who did not comply.[11,12] The lack of relationship between compliance and knowledge might first be explained by the fact that we used a general HF knowledge scale, whereas other studies measured more nutrition-specific knowledge.[28-30] Another explanation for the lack of this relationship is the fact that all patients, whether they were compliant or non-compliant, had a relatively high HF knowledge score. Although knowledge is an important contributing factor in compliant behavior,[31] knowledge alone does not ensure compliance.[32] Patients might have the knowledge that they should restrict their sodium and fluid intake, but find it not important, perceived it as very difficult or are not able to follow the restriction. Earlier studies demonstrated that women were significantly more compliant with sodium restriction compared with men[15] and that older patients were more compliant with sodium restriction compared with their younger counterparts.[10] Our results are confirmative with a study performed by Holst and colleagues,[25] in which also no association between age, gender and compliance was found. Although not statistically significant, patients who were non-compliant with sodium or fluid restriction had a higher mean length of HF symptoms, compared with compliant patients. This difference might implicate that improvement of compliance remains important, even in patients with a substantial length of HF. Patients who were compliant with their sodium restriction more often lived with a partner. From other studies it is known that living alone is associated with poor compliance[32] and that 'eating alone' is a contextual barrier to healthy nutrition.[14] Therefore, despite the lack of statistical significance in this study, further investigation is suggested to obtain more information on the relationship between compliance with dietary sodium and fluid restriction and length of HF and marital status.

This study also confirms that knowledge, beliefs, main demographic variables, and depressive symptoms, although important, are not the only factors that determine the level of compliance. These findings are in line with findings of Dickson and colleagues,[33] who did not find a relationship between knowledge and self-care maintenance. Adding to these results, we found that most of the patients found it important to follow a sodium and fluid restriction, but a higher percentage of non-compliant patients found it difficult to follow these restrictions compared with compliant patients. Regarding sodium restriction, non-compliant patients were more likely to report practical problems compared with compliant

patients. Following a diet might be more challenging than following a pharmacological treatment because it involves changes in habitual behaviors that are frequently imbedded in culture or have social consequences.[34] Regarding fluid restriction, a higher percentage of non-compliant patients in our study also perceived more difficulty with the restriction, compared with compliant patients, although this difference was not statistically significant. Thirst was the most reported problem by both compliant and non-compliant patients. Other studies also found that following a fluid restriction was difficult, especially because of an increase in perceived thirst.[11,35]

The main limitation of this study was the small sample size (n = 84). Although we found differences between compliant and non-compliant patients, these differences were not statistically significant. However, in a larger study sample, these differences might reach the level of statistical significance. Therefore, we think that the observed trends in our study do add to the current knowledge on compliance with dietary sodium and fluid restriction. Furthermore, not all patients had clearly defined their tableware volumes. Therefore, their mean daily fluid intake was calculated using standard volumes. Another limitation was the relatively low NYHA class of the study population; 61% of all patients were of NYHA class II. This might have influenced compliance, because most patients in NYHA II are, according to the guidelines, on a less stringent sodium and fluid restriction, which made it easier for them to comply. Another limitation was that dairy data completed at 12 months after discharge were compared with restrictions prescribed at baseline. Although, in general, dietary sodium and fluid restriction will not change drastically for HF patients, it would be preferable to use a restriction prescribed at 12 months, obtained from reliable sources (e.g. medical record, HF nurse).

Conclusion and implications

In this study, it is found that, in improving compliance, we need to consider additional factors, then the traditional determinants such as knowledge, beliefs, and demographic variables. Although not statistically significant, we found that non-compliant patients perceived their regimen as more difficult compared with their compliant counterparts. Although the differences in perceived difficulty in compliant and non-compliant patients were not statistically significant, we think that these difficulties can affect compliance. More insight in perceived difficulty and reported problems with compliance is needed to improve education of HF patients and help them to cope with these difficulties, resulting in increased compliance. In addition, extra attention should be paid to patients with more stringent prescribed sodium and fluid restrictions.

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Chapter 4

Long-term compliance with nonpharmacologic treatment of patients with heart failure

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Abstract

The aim of this study was to examine long-term compliance with nonpharmacologic treatment of patients with heart failure (HF) and its associated variables. Data from 648 hospitalized patients with HF (mean age 69 ± 12 years, 38% women, mean left ventricular ejection fraction 33 ± 14%) were analyzed. Compliance was assessed by means of self-report at baseline and 1, 6, 12, and 18 months after discharge. Patients completed questionnaires on depressive symptoms, HF knowledge, and physical functioning at baseline. Logistic regression analyses were performed to examine independent associations with low long-term compliance. From baseline to 18-month follow-up, long-term compliance with diet and fluid restriction ranged from 77% to 91% and from 72% to 89%, respectively. In contrast, compliance with daily weighing (34% to 85%) and exercise (48% to 64%) was lower. Patients who were in New York Heart Association functional class II were more often non-compliant with fluid restriction (odds ratio [OR] 1.97, 95% confidence interval [CI] 1.25-3.08). A lower level of knowledge on HF was independently associated with low compliance with fluid restriction (OR 0.78, 95% CI 0.71-0.86) and daily weighing (OR 0.86, 95% CI 0.79-0.94). Educational support improved compliance with these recommendations. Female gender (OR 1.91, 95% CI 1.26-2.90), left ventricular ejection fraction ≥40% (OR 1.55, 95% CI 1.03-2.34), a history of stroke (OR 3.55, 95% CI 1.54-8.16), and less physical functioning (OR 0.99, 95% CI 0.98-0.99) were associated with low compliance with exercise. In conclusion, long-term compliance with exercise and daily weighing was lower than long-term compliance with advice on diet and fluid restriction. Although knowledge on HF and being offered educational support positively affected compliance with weighing and fluid restriction, these variables were not related to compliance with exercise. Therefore, new approaches to help patients with HF stay physically active are needed.

Introduction

Although it has been well established, most studies on determinants of compliance in patients with heart failure (HF) have been cross-sectional or have focused solely on compliance with 1 specific nonpharmacologic recommendation. Data on temporal trends in compliance with cardiovascular medication have been reported previously,[1] but little is known about long-term compliance with nonpharmacologic treatment (i.e. sodium-restricted diet, fluid restriction, daily weighing, and exercise) and its determinants. Non-compliance with nonpharmacologic treatment is related to adverse outcomes[2] and lower quality of life.[3] It is therefore vital to identify those patients who are at risk for non-compliance over a longer period of time, especially considering that studies have shown that non-compliance is a problem in the HF population.[4] It has been suggested that compliance with a specific recommendation might be a marker for compliance with other recommendations or lifestyle changes.[5] Unfortunately, direct comparisons of compliance with different recommendations in the same study population are not available. In the present study, we aimed to address this gap by examining long-term compliance with nonpharmacologic recommendations and by assessing variables associated with long-term compliance.

Methods

We used a descriptive, prospective design with data from the Coordinating Study Evaluating Outcomes of Advising and Counseling in Heart failure (COACH) study. COACH was a randomized, multicenter, controlled study in which 1023 HF patients were included from November 2002 to February 2005.[6, 7] Inclusion criteria were an admission for HF, evidence of a structural underlying heart disease, and age ≥18 years. Exclusion criteria were participation in another study, a planned or recent invasive cardiac intervention, or inability to complete questionnaires. COACH was designed to evaluate the effect of education and counseling by an HF nurse on clinical outcomes in patients with HF. Patients were randomized to either a control group (care as usual, with routine management by a cardiologist) or to 1 of the intervention groups (basic support or intensive support). Along with routine management by a cardiologist, patients in the 2 intervention groups received additional care from an HF nurse. This additional care was provided during hospitalization and after discharge according to protocol and consisted of comprehensive

education and counseling about HF and the HF regimen. Patients in the intensive group had more contact moments with the HF nurse, including ≥1 home visits. Multidisciplinary advice was also part of the intensive intervention.

The study complied with the Declaration of Helsinki and the medical ethics committee granted approval for the protocol. All patients provided written informed consent and were enrolled and examined during a fixed period of 18 months after discharge from the hospital. Assessments, conducted by an independent data collector, took place at index hospitalization (baseline) and 1, 6, 12, and 18 months after discharge (follow-up) at patients' homes. Patients completed questionnaires on compliance, HF knowledge, and quality of life. The presence of depressive symptoms was assessed at baseline and 12 and 18 months after discharge. When patients were not able to complete the questionnaires by themselves, the data collector guided the patients through the questionnaires by reading them the questions. At baseline, clinical variables were retrieved from the patients' medical records and by means of structured interviews. Data on left ventricular function were obtained using standard transthoracic echocardiography. Patients were included in this study on long-term compliance when they completed the compliance questionnaire during ≥4 of 5 assessment moments. Only 1 missing value on each separate recommendation was permitted. When patients had 1 missing value on a specific recommendation during the total follow-up period, this missing value was substituted by the lowest compliance score for that specific recommendation on all other assessments.

The Center for Epidemiologic Studies Depression Scale was used to measure the presence of depressive symptoms.[8] This scale consists of 20 items and measures the presence of depressive feelings and behaviors. A score of ≥16 indicates the presence of depressive symptoms. To differentiate between patients with moderate or severe depressive symptoms, the following cut-off scores were used: 0 to 15 (no depressive symptoms), 16 to 23 (moderate depressive symptoms), and ≥24 (severe depressive symptoms).[9]

Compliance with recommendations on a sodium-restricted diet, fluid restriction, exercise, and daily weighing was measured using the Revised Heart Failure Compliance Scale.[10] Compliance was measured on a 5-point scale (0 = never, 1 = seldom, 2 = half of the time, 3 = mostly, 4 = always). Two HF nurses, experienced in the field of compliance, assessed face validity of the Dutch version of the scale. Patients were defined as compliant with diet, fluid restriction, or exercise when they followed the recommendations always or mostly during the previous week. They were compliant with weighing when they weighed daily or ≥3 times a week during the previous month. When a patient reported to be compliant with a specific recommendation, a score of 1 point was assigned. Because

compliance was measured at 5 different assessment moments (baseline and at 1, 6, 12, and 18 months during follow-up), the compliance score for each recommendation could range from 0 to 5 points. This long-term compliance score was categorized as either low or high, with a score ≤3 defined as low long-term compliance. High long-term compliance indicated compliance at 4 or all 5 assessment moments.

HF knowledge was measured with the Dutch HF knowledge Scale, which consists of 15 multiple choice items (range 0 to 15), with higher score indicating higher levels of HF knowledge. This scale is a reliable and valid instrument for measuring knowledge of HF in general, symptom recognition, and the HF regimen.[11]

Perceived health and physical functioning were assessed using the RAND-36, a self-report questionnaire of general health status similar to the Medical Outcome Study 36-item General Health Survey.[12, 13] Patients were asked to score their general health on a 5-point scale (1 = excellent, 5 = bad). Next, patients were divided into two groups: those who perceived their general health as good to excellent and those who perceived it as fair to bad. The subscale 'physical functioning' consists of 10 items on limitations experienced when performing daily physical activities due to health problems. The total score of the subscale ranges from 0 to 100, with a higher score indicating better functioning.

Descriptive statistics were used to characterize the study population and to examine long-term compliance with the recommendations. For this study, data from the COACH study were used. Compliance with each recommendation was therefore also described separately for patients in the control group and for patients who were assigned to 1 of the intervention groups. Because examining differences in compliance between the 2 intervention groups was not the main focus of the present study, data were pooled for the 2 intervention groups and compared with the control group. To assess which baseline variables were independently associated with low long-term compliance, logistic regression analyses were performed. Low long-term compliance was used as the dependent variable; an odds ratio >1 indicates a higher probability of being low long-term compliant, whereas an odds ratio <1 indicates a lower probability of being low long-term compliant. First, univariate regression analyses were performed to explore which baseline variables were individually associated with low long-term compliance. All theoretically relevant variables for which the Wald test of no association with low long-term compliance had *P*-values < 0.10 were subsequently inserted in a multivariate regression model to determine whether these variables were also independently associated with low long-term compliance. This procedure was conducted for all 4 recommendations. SPSS version 16.0 (SPSS, Inc., Chicago, Illinois) was used to perform the statistical analyses.

Results

Of the 1023 patients participating in COACH, 648 were included in this substudy. A total of 375 (1023-648) patients were excluded: 272 patients died during follow-up period of 18 months, and 103 patients did not complete the compliance questionnaires on ≥4 assessment moments or had >1 missing value on a specific recommendation. Compared to included patients, excluded patients were significantly older (74 vs. 69 years, *P* <0.001), more often lived alone (44% vs. 36%, *P* =0.015), were more often in New York Heart Association (NYHA) functional class III or IV at discharge (58% vs. 44%, *P* <0.001), and more often had an ischemic origin of HF (48% vs. 39%, *P* =0.008). The baseline characteristics of the study population are listed in Table 1.

Table 1. Baseline characteristics (n = 648)	
Age (years), mean ± SD	69 ± 12
Female gender, % (n)	38% (244)
Living alone, % (n)	36% (233)
High educational level, % (n)	11% (74)
LVEF (%), mean ± SD	33 ± 14
LVEF ≥40%, % (n)	32% (187)
NYHA class III or IV at discharge, % (n)	44% (281)
Ischemic origin of HF, % (n)	39% (255)
Length of HF (months), mean ± SD	26.3 ± 48.3
Previous HF admission, % (n)	28% (183)
Depressive symptoms, % (n):	
- Moderate	18% (112)
- Severe	20% (120)
Diabetes mellitus, % (n)	24% (153)
COPD, % (n)	25% (160)
Stroke, % (n)	8% (49)
RAND-36 score	
- Perceived health, fair to bad, % (n)	64% (400)
- Physical functioning, mean ± SD	39 ± 27
Dutch HF Knowledge Scale	
- Total score, mean ± SD	11.3 ± 2.3

COPD *chronic obstructive pulmonary disease;* HF *heart failure;* LVEF *left ventricular ejection fraction;* NYHA *New York Heart Association.*

The mean age of the study population (n = 648) was 69 ± 12 years, 38% were women, and 44% were in NYHA class III or IV at discharge with a mean left ventricular ejection fraction (LVEF) of 33 ± 14%. The mean length of HF symptoms was 26 ± 48 months. Of all patients, 18% had moderate and 20% had severe depressive symptoms. In total, 31% of the patients were in the 'care as usual' group, and 69% were in 1 of the 2 intervention groups.

Compliance with daily weighing (ranging from 34% to 85% at the 5 assessment moments) and compliance with exercise (range 48% to 64%) was lower compared to compliance with a sodium-restricted diet (range 77% to 91%) and fluid restriction (range 72% to 89%) (Figure 1). Compliance with diet at 1 month after discharge from the index hospitalization increased from 77% to 91% and remained stable afterwards. A similar trend was found for compliance with fluid restriction. Compliance with daily weighing increased from 34% to 85% at 1 month but decreased over time to 67% at 18 months. Although compliance with exercise increased at 1 month, it remained at about 60% during follow-up (Figure 1).

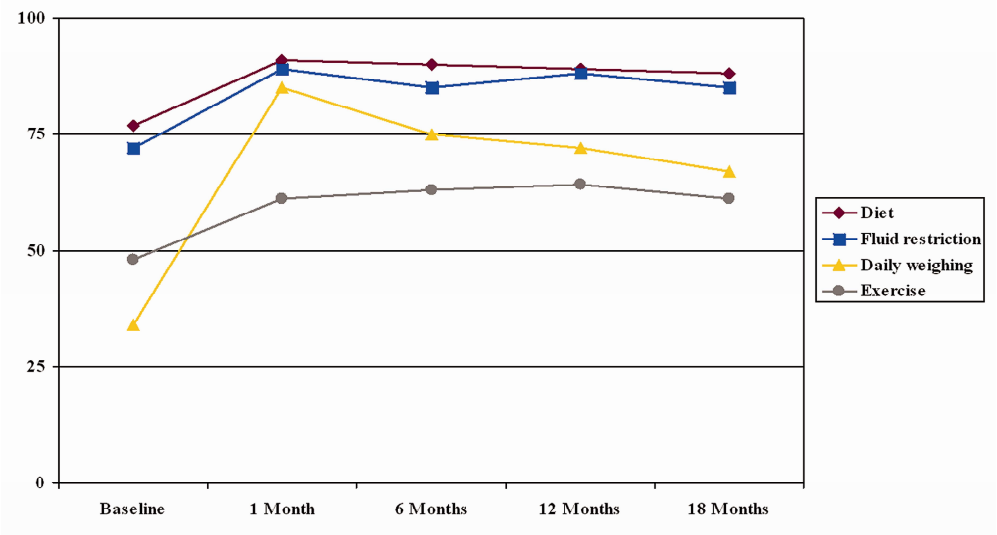

Figure 1. Long-term compliance with nonpharmacologic treatment (n = 648)

Compliance was also examined separately for patients in the control group and for patients in the intervention groups. In the 2 groups, percentages of compliance were also lower for daily weighing and exercise compared to diet and fluid restriction. Compliance with fluid restriction, particularly daily weighing, was higher in the intervention groups (Figures 2 and 3).

Subsequently, low long-term compliance (defined as being compliant at ≤3 of 5 assessment points during baseline and follow-up) with each separate recommendation was examined. Of all patients, 16% demonstrated low compliance in the long term with a sodium- restricted diet and 21% with fluid restriction. In contrast, 41% and 54%, respectively, showed low compliance with daily weighing and exercise. Of all patients who showed low compliance with diet (n = 104), 54% showed low compliance with fluid restriction, 61% with daily weighing, and 82% with exercise. These percentages indicate that low compliance with 1 recommendation does not automatically indicate low compliance with other recommendations in the long term. Similar results were found for low long-term compliance with fluid restriction, weighing, and exercise (Table 2).

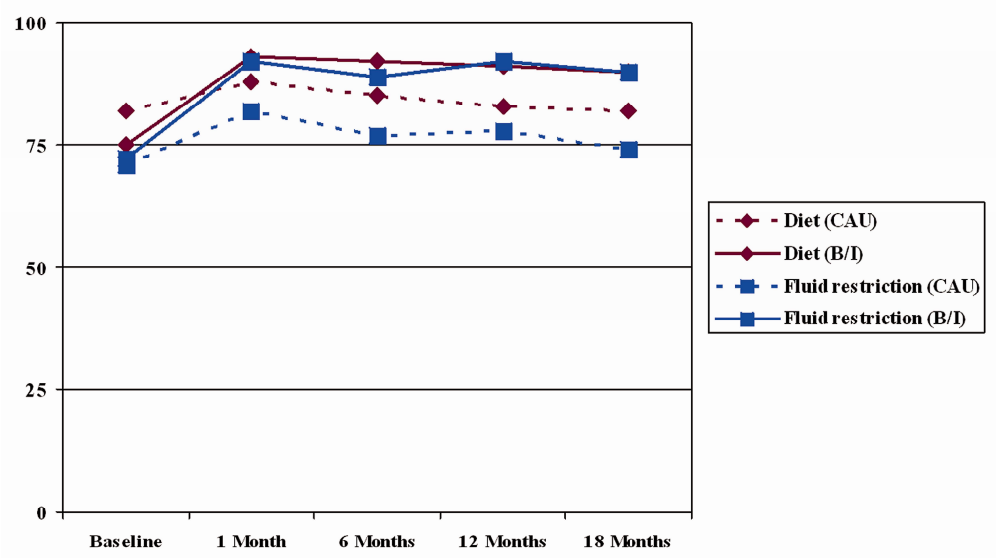

Figure 2. Long-term compliance with a sodium-restricted diet and fluid restriction, Care as usual (CAU) (n = 199) versus basic or intensive support (n = 449)

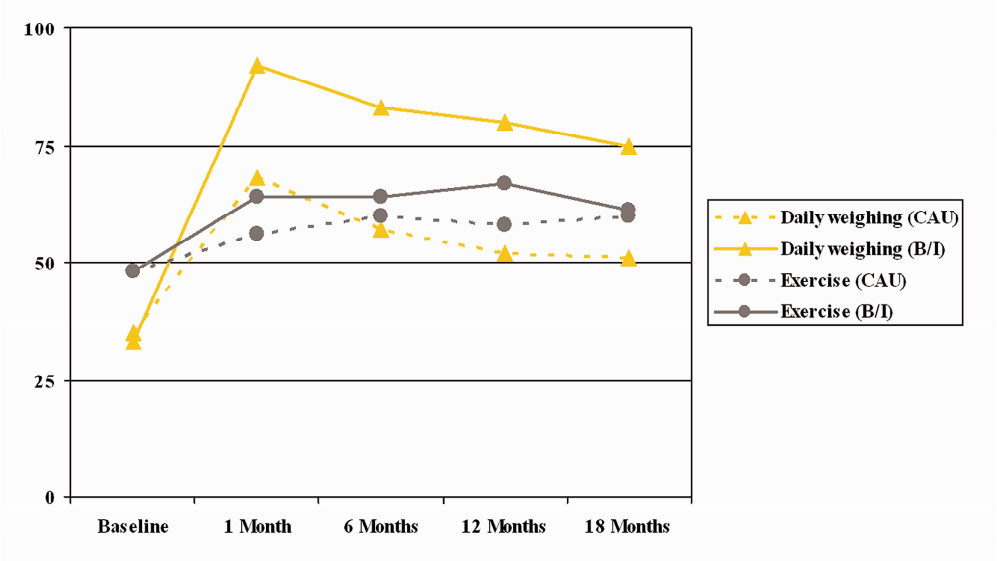

Figure 3. Long-term compliance with daily weighing and exercise care as usual (CAU) (n = 199) versus basic or intensive support (B/I) (n = 449)

Table 2. Low long-term compliance with a particular recommendation related to other recommendations

	Diet	**Fluid restriction**	**Daily weighing**	**Exercise**
Diet (n = 104)		54% (n = 56)	61% (n = 63)	82% (n = 85)
Fluid restriction (n = 138)	41% (n = 56)		65% (n = 89)	79% (n = 109)
Daily weighing (n = 267)	24% (n = 63)	33% (n = 89)		69% (n = 184)
Exercise (n = 352)	24% (n = 85)	31% (n = 109)	52% (n = 184)	

This table lists how many patients with low long-term compliance with a specific recommendation also had low compliance with the other recommendations.

In a multivariate analysis, being in NYHA class II was independently associated with low compliance with fluid restriction. Having more knowledge about HF and being assigned to basic or intensive support were inversely associated with low compliance with fluid restriction and also with low compliance with daily weighing. This indicates that patients with more knowledge or patients who received additional support were more often compliant over a longer period. Women and patients with LVEFs ≥40% were more likely to have low compliance with exercise. In addition, a history of stroke and poor physical functioning due to health problems were associated with low long-term compliance with exercise. No significant associations in univariate or in multivariate analyses were found between compliance with a sodium-restricted diet and possible relevant variables (Table 3).

Discussion

This is the first study to examine long-term compliance with all aspects of nonpharmacologic treatment in patients with HF. The main finding of this study is that it appears to be more challenging for patients to become and to maintain compliant with daily weighing and exercise than with a sodium-restricted diet and fluid restriction. Providing education and counseling improved compliance with fluid restriction and daily weighing in the long term but did not improve compliance with exercise.

Low compliance with daily weighing and exercise has also been demonstrated in previous studies.[10, 14-16] In addition, our study showed that long-term compliance with a particular recommendation does not automatically indicate compliance with other recommendations. This suggests that compliance with the different lifestyle recommendations requires different skills from patients. Furthermore, different factors were found to be associated with low compliance after examining all 4 separate recommendations. However, our data could not identify factors associated with low compliance with a sodium-restricted diet. This was probably caused by the lack of variance in compliance.

Patients with more HF knowledge and those who received additional support from the HF nurse during follow-up were more likely to comply with daily weighing over a longer period. After 1 month of follow-up, compliance with daily weighing increased in patients who received educational support and in those who received care as usual. However, compliance with weighing remained high during follow-up in the intervention groups, while compliance decreased in the care-as-usual group. Although knowledge alone does not ensure compliance,[16] it has nevertheless been confirmed as an important

Table 3. Univariate (P <0.10) and multivariate associations with low long-term compliance*					
Variable	**Unadjusted OR (95% CI)**	***P*-Value**	**Adjusted OR (95% CI)**	***P*-Value**	**Nagelkerke r^2 (C-statistic)**
Low compliance, sodium restriction					0.019
COPD	0.59 (0.34-1.02)	0.06	0.60 (0.35-1.03)	0.06	(0.582)
Basic/intensive support	0.66 (0.43-1.02)	0.06	0.66 (0.42-1.03)	0.07	
Low compliance, fluid restriction					0.137
LVEF ≥40%	1.54 (1.02-2.32)	0.038	1.19 (0.76-1.86)	0.44	(0.685)
NYHA class II	1.68 (1.13-2.50)	0.010	1.97 (1.25-3.08)	0.003	
Stroke	2.10 (1.13-3.91)	0.019	1.57 (0.77-3.21)	0.22	
HF knowledge	0.77 (0.71-0.84)	<0.001	0.78 (0.71-0.86)	<0.001	
Basic/intensive support	0.47 (0.32-0.69)	<0.001	0.50 (0.32-0.77)	0.002	
Low compliance, daily weighing					0.150
Age (years)	1.03 (1.01-1.04)	<0.001	1.01 (0.99-1.03)	0.19	(0.688)
Living alone	1.49 (1.07-2.06)	0.017	1.26 (0.86-1.83)	0.24	
High educational level	0.61 (0.36-1.03)	0.06	0.81 (0.45-1.44)	0.47	
LVEF ≥40%	1.77 (1.25-2.52)	0.001	1.44 (0.98-2.11)	0.06	
HF knowledge	0.85 (0.79-0.91)	<0.001	0.86 (0.79-0.94)	0.001	
Basic/intensive support	0.32 (0.23-0.45)	<0.001	0.32 (0.21-0.46)	<0.001	

Table 3. (Continued) Univariate (P <0.10) and multivariate associations with low long-term compliance*					
Variable	**Unadjusted OR (95% CI)**	***P*-Value**	**Adjusted OR (95% CI)**	***P*-Value**	**Nagelkerke r^2 (C-statistic)**
Low compliance, exercise					0.180
Age (years)	1.03 (1.01-1.04)	<0.001	1.02 (0.99-1.04)	0.06	(0.716)
Female gender	1.83 (1.32-2.53)	<0.001	1.91 (1.26-2.90)	0.002	
Living alone	1.36 (0.98-1.88)	0.07	0.82 (0.54-1.24)	0.34	
LVEF ≥40%	1.57 (1.10-2.23)	0.013	1.55 (1.03-2.34)	0.036	
NYHA class II	0.63 (0.46-0.86)	0.004	0.90 (0.60-1.35)	0.61	
Previous HF admission	1.35 (0.95-1.90)	0.09	1.30 (0.83-2.03)	0.25	
Diabetes Mellitus	1.41 (0.98-2.04)	0.07	1.09 (0.69-1.73)	0.72	
Stroke	3.56 (1.75-7.27)	<0.001	3.55 (1.54-8.16)	0.003	
Depressive symptoms					
- No symptoms	1.00 (reference)		1.00 (reference)		
- Moderate symptoms	1.80 (1.16-2.77)	0.008	1.47 (0.88-2.46)	0.14	
- Severe symptoms	1.73 (1.14-2.63)	0.011	1.04 (0.61-1.75)	0.89	
Total HF symptoms	1.10 (1.02-1.17)	0.010	1.01 (0.92-1.11)	0.78	
Perceived health (fair-bad)	1.93 (1.39-2.68)	<0.001	1.28 (0.84-1.94)	0.25	
Physical functioning	0.98 (0.98-0.99)	<0.001	0.99 (0.98-0.99)	0.006	
HF knowledge	0.86 (0.80-0.93)	<0.001	0.93 (0.85-1.02)	0.14	

** The multivariate model includes all variables listed.*

CI *confidence interval;* COPD *chronic obstructive pulmonary disease;* HF *heart failure;* LVEF *left ventricular ejection fraction;* NYHA *New York Heart Association;* OR *odds ratio.*

determinant of compliance in HF research.[17-20] An explanation for low compliance with weighing could be that many patients with HF do not recognize the importance of daily weighing to check for fluid retention.[16] Also, having a stable weight over a longer period is another reason why patients weigh themselves less often.[21] Our study showed that providing adequate education on the importance of daily weighing is effective on increasing and maintaining compliance. Patients with more knowledge about HF and those who received educational support during follow-up were also more likely to comply with fluid restriction in the long-term. In contrast, patients in NYHA class II more often had low long-term compliance with fluid restriction compared to those in NYHA class III or IV. A possible explanation for this difference could be that patients in lower NYHA classes are less motivated to comply with the recommendations on fluid intake because they do not experience many of the symptoms associated with HF.

Besides low compliance with daily weighing, we also confirmed low long-term compliance with recommendations on exercise.[22] Compliance with exercise also influenced the results of Heart Failure: A Controlled Trial Investigating Outcomes of Exercise Training (HF-ACTION). Patients who fully complied with the exercise intervention had better outcomes, but only 30% of the patients actually did. Consequently, low compliance with the training regimen may have led to a failure to detect a significant effect of exercise training on primary outcomes.[22] Our study showed that less physical functioning and a history of stroke, resulting in physical impairment, were independently associated with low long-term compliance with exercise. Additionally, older patients tended to be more often non-compliant, which suggests that older patients may have less energy or experience more physical symptoms, which in turn might affect their ability to comply.[10, 20] HF symptoms and NYHA class were not associated with compliance with exercise. This indicates that physical symptoms and limitations related to factors such as older age and comorbidities possibly play a larger role in non-compliance with exercise than physical limitations related to HF itself. Health care providers should take these possible physical limitations into consideration and should try to tailor recommendations on exercise to the specific needs of individual patients.

In contrast to compliance with daily weighing, which improved in patients who received education and counseling according to the COACH study intervention, this intervention was not effective in increasing compliance with exercise. This suggests that other interventions are needed to improve compliance in the long-term. Although it is known that motivational strategies, such as setting goals, giving feedback, and solving

problems might be effective in the short term, further research is needed to formulate strategies in order to sustain physical activity in patients with HF.[23]

Our study had some limitations. First, we used an arbitrary cut-off score to differentiate between patients with low and high long-term compliance. Second, data were collected by means of self-report, which may be susceptible to social desirability bias. Patients either completed questionnaires by themselves, or the data collector read them the questions, which may have affected patients' responses. Because it is not known which patients received assistance with completing the questionnaires, possible mode effects could not be assessed. Nevertheless, all data collectors were independent and trained according to protocol. A final limitation concerns the exclusion of patients who died during follow-up or who had >1 missing value on compliance data. This may have biased our data on long-term compliance, because mortality or not completing questionnaires might be due to non-compliance with nonpharmacologic treatment.

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Chapter 5

Motivation and perceived control in compliance with exercise recommendations in heart failure patients

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Submitted

Abstract

Background

Exercise recommendations are important aspects of the non-pharmacological heart failure (HF) regimen. The purpose of this study was to assess the association of intrinsic and extrinsic motivation and perceived control with compliance with exercise in HF patients.

Methods

In total, 73 HF patients (mean age 61 ± 14 years, 32% female, 34% NYHA-class III) completed questionnaires on compliance with exercise recommendations, intrinsic and extrinsic (external-, introjected-, and identified regulation) motivation and perceived control. Logistic regression analyses were performed to examine independent associations between motivation, perceived control and compliance.

Results

Of all patients, 59% (n = 43) reported to comply with exercise recommendations. Compliant patients considered physical activity more often as important, compared with non-compliant patients (95% vs. 73%, P <.01). Patients with more intrinsic motivation were more likely to comply (odds ratio [OR] 2.51, 95% confidence interval [CI] 1.35-4.67). Regarding extrinsic motivation, only identified regulation was independently associated with compliance (OR 7.68, 95% CI 2.35-25.11). Perceived control was not associated with compliance with exercise.

Conclusions

Patients, who enjoy exercise or see it as a tool to obtain beneficial outcome, were more likely to comply with exercise recommendations. Feelings of guilt or external pressure performed by others were not associated with compliance.

Introduction

The prevalence of heart failure (HF) is rising, because of older age and increased survival from ischemic and other cardiovascular diseases.[1] Dysnpea and fatigue, which are typical symptoms of HF, have a significant impact on exercise capacity and quality of life.[2,3] Exercise training and regular daily physical activity can result in an improvement in functional capacity, quality of life and a reduction of HF symptoms.[4-6]

According to international guidelines, regular, moderate exercise activity as part of a management program is recommended for all patients with HF.[1,7] Since there is no universal exercise prescription in HF, a tailored approach is desirable.[8] Exercise recommendations are the most important aspects of the non-pharmacological treatment, since non-compliance with these recommendations is associated with an increased risk of mortality and readmissions.[9] However, non-compliance with exercise recommendations is common in HF patients and it is estimated that about 50% of the HF patients do not comply.[10] Limitations in physical functioning, the presence of physical symptoms and lack of time are common barriers in HF patients to comply with exercise recommendations. Motivation is another important aspect in understanding non-compliance.[11]

The Self-Determination Theory[12] has been a major focus of motivation research. Considering physical activities, this theory distinguishes between intrinsic and extrinsic motivation to engage in these activities.[13] Intrinsic motivation indicates that behaviour is performed for the pleasure or satisfaction derived from the process of participation in the activity. Experience of enjoyment from exercise participation is an important aspect in order to understand exercise compliance.[14] In contrast, extrinsic motivation indicates that behaviour is performed for reasons different from the enjoyment of being involved in the activity, and consists of different aspects. *External regulation* indicates that behaviour is driven by externally controlled rewards or punishment. For example, patients can participate in physical activities out of pressure applied by their spouse or physician. *Introjected regulation* indicates that individuals engage in the activity by applying pressure on themselves; patients participate in the activity in order to avoid feelings of guilt or negative self-esteem. An example is an individual who participates in physical activity out of feelings of guilt or dissatisfaction with their body weight. *Identified regulation* indicates that individuals participate in an activity, because they believe it is important for personal development or for gaining beneficial outcome (i.e. to derive physical health benefits).

Patients, who believe that exercise is beneficial for their health, may be therefore more likely to comply with these recommendations. Another factor that can underlie compliance with exercise recommendations with respect of beneficial outcome is perceived control.

Perceived control can be defined as the perception or belief that individuals have a coping response that can positively influence adverse events or circumstances.[15] From a HF perspective, perceived control can be conceptualized as the patients' perception about their ability to control their heart, HF symptoms, and lives.[16] Perceived control is a predictor of physical symptom status,[2] and higher perceived control is associated with more adequate self-care behaviour[16] and better psychosocial recovery after a cardiac event.[17] Perceived control is amendable to change and can be increased by providing specific education and counseling.[18]

Although barriers and other factors related to non-compliance with exercise have been described previously, little is known about the role of intrinsic and extrinsic motivation and perceived control in compliance in HF patients. Most physical activities entail both intrinsic and extrinsic motives; people often maintain their exercise activities not only for enjoyment, but also because they have something to gain in it (i.e. improving their health or shape).[19] However, the role of these mechanisms in compliance with exercise recommendations in HF patients has not been described yet. Therefore, the aims of the present study were to examine differences between compliant and non-compliant patients and to assess the associations between intrinsic and extrinsic motivation, perceived control and compliance with exercise recommendations.

Methods

The study used a descriptive, cross-sectional design with data from 73 HF patients, who were recruited from 2 hospitals in the Netherlands (University Medical Center Groningen and Martini Ziekenhuis Groningen). Inclusion criteria were diagnosis of HF confirmed by the cardiologist, evidence of structural underlying heart disease, optimal medication, NYHA (New York Heart Association) functional class I-III and at least 18 years of age. Exclusion criteria were a life expectance <1 year, a planned or recent invasive cardiac intervention, ventricular tachycardia and atrial fibrillation during increased physical activity, uncontrolled diabetes, recent lung embolism, inability to walk or cycle, or to complete questionnaires, or participation in another study. The study complied with the Declaration of Helsinki and the Medical Ethics Committee granted approval for the protocol.

During a visit to the HF clinic, patients who met the in-and exclusion criteria were informed about the study by the HF nurse, and patients who were interested were invited to participate. Patients received verbal and written information about the study and its procedure by the principal investigator and all participating patients provided written informed consent. At the end of the visit to the HF clinic, participating patients were provided with the data collection formats by the principal researcher. Physical activity was measured by accelerometry for 2 consecutive weekdays, and patients were asked to complete the questionnaires at home during this data collection period. Patients were instructed to return the questionnaires and the accelerometer to the principal researcher by post.

Compliance with exercise recommendations

Compliance with exercise recommendations was measured with the Revised Heart Failure Compliance Scale.[20] Compliance was measured on a 5-point scale (0 = 'never', 1 = 'seldom', 2 = 'half of the time', 3 = 'mostly', 4 = 'always'). The original US version was tested for reliability and validity[20] and for the Dutch version of the scale, two HF nurses experienced in the field of compliance assessed face validity.

Patients were defined as compliant with exercise recommendations when they reported to follow the recommendations 'always' or 'mostly' during the last week, which is confirmative with other studies.[9,20,21] Additionally, importance of regular physical activity and difficulty with compliance with exercise recommendations was assessed on a similar scale. Patients were differentiated into patients who considered regular physical activity as 'not important' and '(very) important' and into patients who find it 'not difficult' or '(very) difficult' to comply.

Intrinsic and extrinsic motivation

To examine motivation for engaging in physical activity, the Self-Regulation Questionnaire-Exercise (SRQ-E) was used. This scale is a component of the Self-Regulation Questionnaires assessing domain-specific individual differences in the types of motivation or regulation.[22] The SRQ-E is a reliable and valid instrument[23,24] and this 16-item scale consists of 4 subscales; one representing intrinsic motivation, and 3 subscales representing extrinsic motivation; external regulation, introjected regulation and identified regulation. Each subscale consist of 4 items; patients were asked to indicate how true each of the items was a reason for them to exercise regularly (1 = 'not at all true', 7 = 'very true'). The mean of the total score of each separate subscale was used to indicate the score

Table 1. Examples of items from each of the 4 subscales of the Self-Regulation Questionnaire-Exercise (SRQ-E)

	I try to exercise on a regular basis:
Intrinsic motivation	*Because I enjoy exercising.*
External regulation	*Because I worry that I would get in trouble with others if I did not.*
Introjected regulation	*Because I feel guilty if I do not exercise regularly.*
Identified regulation	*Because feeling healthier is an important value for me.*

on the 4 different components of motivation. Examples of items from each subscale are presented in Table 1.

Perceived control

To assess the amount of perceived control regarding HF and HF symptoms, the Control Attitude Scale-Revised (CAS-R)[25] was used. The CAS-R consists of 8 items (Table 2) and perceived control was measured on a 5-point Likert scale (1= 'Completely disagree', 5 = 'Completely agree'). The scale theoretically ranges from 8 to 40, with higher scores indicating more perceived control.

Other study measurements

Clinical and demographic variables were assessed from the patients' medical record. Depressive symptoms and anxiety were assessed with the 14-item Hospital Anxiety and

Table 2. Items of the Control Attitude Scale-Revised (CAS-R)

- If I do all the right things, I can successfully manage my heart condition.
- I can do al lot of things myself to cope with my heart condition.
- When I manage my personal life well, my heart condition does not bother me as much.
- I have considerable ability to control my symptoms.
- No matter what I do, or how hard I try, I just can't seem to get relief from my symptoms.*
- I am coping effectively with my heart condition.
- Regarding my heart problems, I feel lots of control.
- Regarding my heart problems, I feel helpless.*

* *scoring is reversed on these items.*

Depression Scale (HADS).[26] The HADS measures the presence of depressive symptoms and the feeling of anxiety during the past week on a 4-point Likert scale using 2 subscales. The depression subscale consists of 7 items and ranges theoretically from 0 to 21. A higher score indicates more depressive symptoms. The anxiety subscale also consists of 7 items (range 0-21) with a higher score indicating higher state of anxiety. The Dutch version of the HADS has been validated previously.[27] Daily physical activity was measured using the 2-axis accelerometer SenseWear® Pro3 Armband (BodyMedia, Inc., Pittsburgh, PA). Along with gender, age, height, and weight, data from the SenseWear® are incorporated into proprietary algorithms to estimate energy expenditure and physical activity duration. Physical activity was measured for 2 consecutive weekdays (48 hours) and outcome measure of the SenseWear® concerning physical activity used in this study was the mean number of steps/day.

Statistical analysis

Descriptive statistics were used to characterize the study population. Differences between compliant and non-compliant patients were tested with Chi-square tests or Fisher's exact tests for dichotomous variables and Mann-Whitney tests for continuous variables. A *P*-value < 0.05 (two-tailed) was considered as statistical significant. To examine the role of the separate aspects of motivation and perceived control, logistic regression analyses were performed, using stepwise enter methods. In these models constructed for motivation and perceived control, NYHA-class, left ventricular ejection fraction (LVEF), presence of comorbidity and perceived difficulty with compliance were inserted as covariates in the second step (based on theoretical assumptions and an univariate *P*-value <.15). SPSS 16.0 statistical software was used for statistical analyses (SPSS Inc, Chicago, IL).

Results

Characteristics of the study population

A total of 109 HF patients who met the in- and exclusion criteria were informed about the study by the HF nurse and 82 (n = 89) patients agreed to participate in the study, 16 of these 89 patients had incomplete data and were excluded from analysis. Excluded patients had a significantly higher LVEF (38% vs. 35%, *P* =.03) and tended to be more often in NYHA-class I-II, compared with included patients.

The mean age of the study population (n = 73) was 61 ± 14 years, 32% of all patients were female and 34% were in NYHA class III, with a mean LVEF of 35 ± 14%.

Diabetes (23%, n = 17) and chronic obstructive pulmonary disease (COPD) (12%, n = 9) were the two most common comorbidities in the study population (Table 3).

Table 3. Characteristics of the study population and differences between compliant and non-compliant patients

	All Patients (n = 73)	**Compliant Patients (n = 43)**	**Non-compliant Patients (n = 30)**	***P*-Value**
Demographics				
Age (years), mean ± SD	61 ± 14	60 ± 14	63 ± 13	.31
Female gender, % (n)	32% (23)	35% (15)	27% (8)	.61
Living with partner, % (n)	75% (55)	77% (33)	73% (22)	.79
Employed, % (n)	28% (19)	34% (13)	21% (6)	.28
High Education, % (n)	17% (12)	19% (8)	13% (4)	.75
Clinical variables				
NYHA Class, % (n):				.10
- I/II	66% (48)	58% (25)	77% (23)	
- III	34% (25)	42% (18)	23% (7)	
LVEF (%), mean ± SD	35 ± 14	32 ± 14	40 ± 14	.03
BMI, mean ± SD	28.0 ± 5.3	28.1 ± 5.0	27.9 ± 5.7	.79
Comorbidity				
Comorbidity, yes, % (n)	56% (41)	49% (21)	67% (20)	.13
Diabetes, % (n)	23% (17)	16% (7)	33% (10)	.10
COPD, % (n)	12% (9)	12% (5)	13% (4)	1.00
Stroke, % (n)	4% (3)	7% (3)	0%	.26
Other, % (n)	37% (27)	30% (13)	47% (14)	.15
HADS				
Depression, mean ± SD	5.3 ± 3.8	5.3 ± 4.2	5.4 ± 3.1	.60
Anxiety, mean ± SD	5.4 ± 3.6	5.5 ± 3.8	5.2 ± 3.5	.92
Physical activity				
Mean steps/day ± SD	5409 ± 3261	5847 ± 3585	4706 ± 2575	.26
'(highly) important', % (n)	86% (63)	95% (41)	73% (22)	.01
Compliance				
'(very) difficult', % (n)	26% (19)	14% (6)	45% (13)	.01

BMI *body mass index;* COPD *chronic obstructive pulmonary disease;* HADS *Hospital Anxiety and Depression Scale;* LVEF *left ventricular ejection fraction;* NYHA *New York Heart Association.*

Compliance with exercise recommendations

In total, 59% (n = 43) of all patients reported to be compliant with exercise recommendations; 38 reported that they complied 'mostly', 5 'always' complied. Of all non-compliant patients (n = 30), 12 reported that they complied 'half of the time' and 14 'seldom' complied. Only 4 patients reported that they 'never' complied with the exercise recommendations. Of all patients, 86% (n = 63) considered regular daily physical activity as (very) important and 26% (n = 19) found it (very) difficult to comply with the exercise recommendations. In total, 65% reported that they received specific recommendations on exercise by the physician. Similar rates for received recommendations were found for compliant and non-compliant patients (70% vs. 58%, *P* =.43).

Differences between compliant and non-compliant patients

Almost all compliant patients (95%) considered regular physical activity as (highly) important. In contrast, a lower percentage of non-compliant patients considered physical activity as (highly) important (73% vs. 95%, *P* <.01). A significantly higher percentage of non-compliant patients reported difficulty with compliance, compared with their compliant

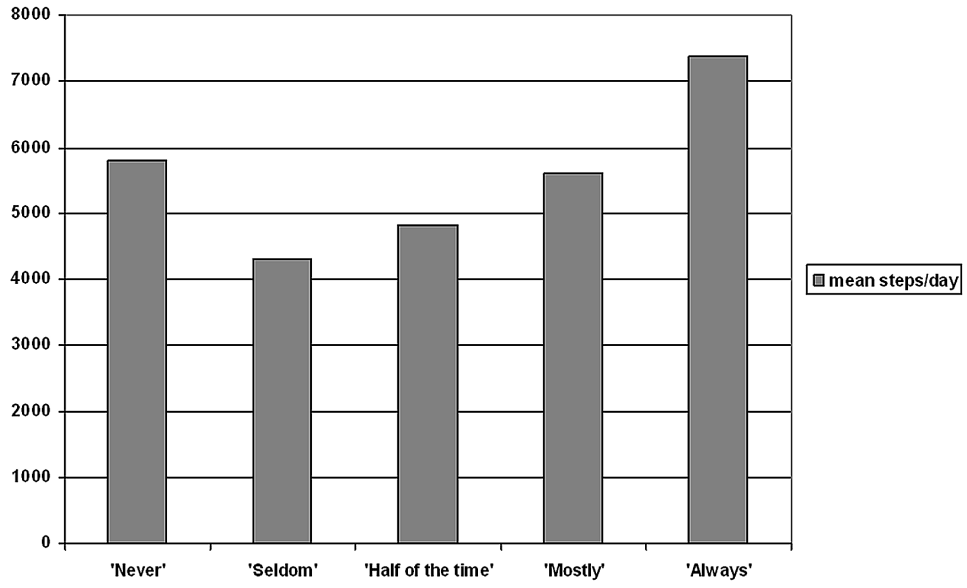

Figure 1. Compliance and number of mean steps/day

counterparts (45% vs. 14%, *P* <.01). Non-compliant patients had a significantly higher LVEF 40% vs. 32%, *P* =.03) and tended to be more often in NYHA-class I-II.

Of all patients, 13 had insufficient SenseWear® data. Therefore, data on physical activity are only presented for patients with complete SenseWear® data (n = 60). No significant differences in physical activity (i.e. number of mean steps/day) were found between compliant and non-compliant patients (5847 ± 3585 vs. 4706 ± 2575, *P* =.26) (Table 3). Figure 1 presents the distribution of the mean number of steps/day with respect to the scores of self-reported compliance with exercise recommendations (0 = 'never'; 1 = 'seldom'; 2 = 'half of the time'; 3 = 'mostly'; 4 = 'always').

Motivation

Intrinsic motivation (5.5 ± 1.2 vs. 4.0 ± 1.3, *P* <.01) and identified regulation (6.2 ± .7 vs. 4.7 ± 1.3, *P* <.01) was significantly higher in compliant patients, compared with non-compliant patients. No significant differences in external- and introjected regulation between compliant and non-compliant patients were found, indicating that compliance with exercise recommendations is not related to motivational aspects with respect to feelings of guilt derived from themselves or punishment applied by others (Table 4).

Table 4. Differences in intrinsic- and extrinsic motivation and perceived control between compliant and non-compliant patients

	Compliant Patients (n = 43)	**Non-compliant Patients (n = 30)**	***P*-Value**
Intrinsic motivation, (mean ± SD)			
Intrinsic motivation (SRQ-E)	5.5 ± 1.2	4.0 ± 1.3	<.01
Extrinsic motivation, (mean ± SD)			
External regulation (SRQ-E)	2.4 ± 1.4	2.3 ± 1.2	.96
Introjected regulation (SRQ-E)	3.6 ± 1.6	3.0 ± 1.4	.17
Identified regulation (SRQ-E)	6.2 ± 0.7	4.7 ± 1.3	<.01
Perceived Control, (mean ± SD)			
Control Attitude Scale (CAS-R)	28.3 ± 5.7	25.8 ± 5.3	.06

After adjustment for NYHA-class, LVEF, presence of comorbidity and perceived difficulty with compliance, intrinsic motivation was also independently associated with compliance (odds ratio [OR] 2.51, 95% confidence interval [CI] 1.35-4.67) meaning that patients who enjoy exercise were more likely to comply. Identified regulation was also independently associated with compliance with exercise (OR 7.68, 95% CI 2.35-25.11), indicating that patients who believed that physical exercise is important for their health, were more likely to comply (Table 5).

Perceived control

Patient who were compliant with exercise recommendations tended to have a higher score on the CAS-R than non-compliant patients (29.1 ± 4.9 vs. 26.0 ± 5.2, *P* =.06), indicating that compliant patients tended to have a higher amount of perceived control (Table 4).

In a multivariable analysis, after adjustment for NYHA-class, LVEF, presence of comorbidity and perceived difficulty with compliance, a higher amount of perceived control regarding HF and HF symptoms was not related to compliance with exercise recommendations (OR 1.06, 95% CI .96-1.18) (Table 5).

Table 5. Unadjusted and adjusted odds ratio for compliance with exercise recommendations.

	Unadjusted OR (95% CI)	**Adjusted OR (95% CI)[a]**	***P*-value[b]**
Intrinsic motivation			
Intrinsic motivation (SRQ-E)	2.39 (1.47-3.89)	2.51 (1.35-4.67)	<.01
Extrinsic motivation			
External regulation (SRQ-E)	1.05 (0.72-1.53)	1.08 (0.72-1.64)	.71
Introjected regulation (SRQ-E)	1.28 (0.91-1.80)	1.20 (0.83-1.75)	.33
Identified regulation (SRQ-E)	6.71 (2.56-17.60)	7.68 (2.35-25.11)	<.01
Perceived Control			
Control Attitude Scale (CAS-R)	1.10 (1.01-1.20)	1.06 (0.96-1.18)	.26

a. *Adjusted for NYHA-functional class, LVEF, comorbidity and difficulty with compliance.*
b. *P-value for Odds Ratio after adjustment.*

Discussion

The main findings of this study are that intrinsic motivation and identified regulation, which is a component of extrinsic motivation, are associated with compliance with exercise recommendations in HF patients. Patients, who enjoy exercise activity *(intrinsic motivation),* and those who see it as a tool to obtain beneficial outcome *(identified regulation)* were more likely to comply. Perceived control was not associated with compliance with exercise recommendations. Compliant patients considered regular physical activity as more important and found it less difficult to comply with exercise recommendations, compared with non-compliant patients.

About 40% of all patients reported that they were non-compliant with exercise recommendations, which is comparable with other studies.[10, 21] Of all patients, 35% reported that they did not receive specific recommendations on exercise from their physician. These patients could have received recommendations from other health care providers, such as a HF nurse. However, at the same time, this may also indicate that, in general, this part of the non-pharmacological HF regimen is still poorly implemented in daily clinical practice.[28] No significant differences between compliant and non-compliant patients in whether or not receiving advice about physical activity from the physician was found.

One of the aims of this study was to assess the role of intrinsic- and extrinsic motivation in compliance with exercise recommendations. We found that intrinsic motivation was associated with exercise compliance, indicating that patients who enjoy exercise activities were more likely to comply, independent of their disease severity, health status and perceived difficulty to comply. Regarding extrinsic motivation, identified regulation was independently associated with compliance with exercise recommendations. This indicates that compliant patients more often consider exercise activities as a tool to obtain beneficial outcome, such as minimizing symptoms or to stay healthy. This is in line with the finding that 95% of the compliant patients reported that regular physical activity was (very) important to them.

Although the importance of extrinsic motivation in evaluating reasons for engaging in exercise performance has been recognized,[19] the other components of extrinsic motivation (external- and introjected regulation) were not related to compliance. This is in line with a previous study on motivation and exercise enjoyment, demonstrating that high levels of both identified regulation and intrinsic motivation corresponded with higher scores on exercise enjoyment.[29] Our results on motivation and compliance with exercise

recommendations indicate that compliant patients are complying from a self-determined perspective (because they enjoy exercise or in order to obtain beneficial outcome), instead of for the opinion of, or pressure applied by, other persons (i.e. partner, health care provider). It is suggested that professionals need to avoid blaming the patients for low compliance, as this may lead to guilt and a sense of failure which may result in discontinuation of exercise activity.[11] Our study showed that these external pressure performed by others does not seem to play a role in compliance with exercise recommendations. Furthermore, patients are not more likely to comply in order to avoid feelings of guilt or negative self-esteem, since introjected regulation was not associated with compliance with exercise recommendations.

Identified regulation may also play a role in compliance with other aspects of the regimen, besides exercise recommendations in HF patients. The importance of beliefs in compliance with the regimen strengthens this assumption. Beliefs about the HF regimen, consisting of perceived barriers (i.e. potential negative consequences) and benefits (i.e. believed effectiveness), are concepts with underlying mechanisms similar to identified regulation when applied to health actions. In a previous study, we demonstrated that beliefs about the regimen play an important role in compliance in HF patients.[21] From this perspective, it is also important that patients should have the beliefs that complying with the regimen will positively affect their disease and health status, by reducing barriers and increasing benefits. Therefore, identified regulation seems to be a crucial component in order to increase compliance, not only with exercise recommendations, but also with the other (non)pharmacological aspects of the HF regimen.

Compliant patients tended to have more perceived control regarding their HF and HF symptoms, compared with non-compliant patients. Despite the fact that perceived control was not independently associated with compliance with exercise recommendations, we still see perceived control as a potential important aspect considering compliance in general, since it was found previously that HF patients with more perceived control were more likely to perform adequate self-care behaviours.[16] Furthermore, one might also suggest that patients who belief that self-care behaviours (such as complying with the regimen) are tools to obtain beneficial outcome considering their health status, may also perceive more control of their health by engaging in these behaviours.

Although it is known that depressive symptoms are associated with compliance and outcome in HF,[21,30,31] depression was not related to adherence with exercise recommendations is our study. This can be explained by a lack of variance in depressive

symptoms, since the presence of these symptoms was relatively low in the entire study population.

No significant differences in daily physical activity were found between compliant and non-compliant patients. Although patients who complied ‘always’ were more physically active, compared with patients who were less often compliant with exercise recommendations, it is unknown what kind of specific recommendations patients received. Therefore, more daily physical activity does not automatically mean better compliance; it is possible that patients were more physically active, than actually was recommended, or that patients with low daily physical activity were actually compliant, because they were instructed to do so.

A limitation of this study is the small sample size. Furthermore, no data were available on what type of specific recommendations patients received by their physician, which made it impossible to compare given recommendations with actual daily activity measured by accelerometry to determine compliance with these recommendations. Of all patients, 35% reported that they did not receive specific recommendations from their physician. Another limitation is, therefore, that it is not clear whether or not these patients possibly received recommendations from another health-care provider, such as a HF nurse.

Conclusion and implications

Patients, who enjoy exercise or see it as a tool to obtain beneficial outcome were more likely to comply with exercise recommendations. Feelings of guilt or external pressure performed by others did not seem to play a role in compliance. Health care providers should be aware of this when implementing education and counselling with respect to compliance with exercise recommendations into daily practice. Providing information about the importance of exercise activities with respect of clinical outcome may help increase identified regulation in HF patients, and therefore compliance. In order to make it less difficult to comply, health care providers should discuss which type of exercise activity HF patients should like to engage in, which can be important to (intrinsically) motivate patients and to help them to stay physically active.

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Part II

Self-care behaviour: Delay

Chapter 6

Depression and the delay between symptom onset and hospitalization in heart failure patients

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Abstract

Aims

Heart Failure (HF) patients frequently suffer from episodes of deterioration and may need medical treatment. An adequate reaction from the patient is needed to decrease the delay between the onset of deterioration and consulting a medical professional (i.e. consulting behaviour). The aim of the present study was to evaluate whether depressive symptoms are associated with the duration of the delay between the onset of symptoms of worsening HF and hospitalization, and to examine how consulting behaviour correlates to depressive symptoms and delay in HF patients.

Method and results

Data on the time between the onset of symptoms of worsening HF and hospitalization, depressive symptoms, and self-care behaviour were collected in 958 HF patients (37% female, age 71 ± 11 years, New York Heart Association functional class II-IV), using validated questionnaires. The median delay time of the total sample was 72 h (ranging from 0 to 243 days). Patients with depressive symptoms delayed longer compared with those without depressive symptoms (120 vs. 54h, P =0.001). Patients with depressive symptoms had a 1.5 times higher risk for a delay of ≥72 h, independent of demographic and clinical variables (P =0.008). Consulting behaviour did not correlate with depressive symptoms but was weakly associated with delay (r = -0.07, P =0.03).

Conclusion

Heart failure patients with depressive symptoms have a significantly longer delay between HF deterioration and hospital admission. Interventions designed to improve the consulting behaviour in HF patients with depressive symptoms may have a limited effect on delay. Further research is needed to obtain more insight into the mechanisms underlying the relationship between delay and depression.

Introduction

Heart failure (HF) has become one of the most significant health problems in the western world today and is one of the most common reasons for hospital admission, particular in people older than 65 years.[1] Many HF patients wait a considerable time before contacting a health care provider following the onset of symptoms of deterioration. It has been reported that up to 50% of patients wait 3-7 days.[2-4] In patients with acute coronary syndromes (ACS), the intensity of the onset of symptoms is often associated with anxiety and decreased times of delay.[4,5] In contrast, HF patients often experience a gradual increase in symptoms over days or weeks, and many patients do not appreciate the importance of these symptoms. Instead, they develop alternative 'coping' strategies to deflect the burden of the symptoms such as resting, sleeping in a recliner, avoiding walking up the stairs, or waiting for the symptoms to go away.[4,5] However, during this period of untreated symptoms, HF patients are vulnerable, particularly to triggering of arrhythmias, and therefore, strategies aimed at improving awareness about deterioration in HF patients are warranted.[6]

Symptom recognition and adequate response to symptoms are all elements of adequate self-care behaviour in HF patients. This means that patients have to perform activities such as daily weighing, taking medication, and restricting sodium intake to maintain their physical stability.[7] In case of deterioration, patients need to take decisions and develop strategies to restore stability,[8] such as increasing diuretic doses. Patients also need to evaluate the effect of these actions and decide when it is appropriate to consult a health care provider.[7] Approximately 20-40% of HF patients suffer from depressive symptoms.[9,10] Patients with HF and depressive symptoms have worse quality of life[11] and a higher risk for mortality and hospital readmissions.[12,13] This might be due to the fact that depressive symptoms are associated with difficulties in taking medication,[14] that patients with depressive symptoms perceive less benefits from lifestyle changes or have difficulty in seeking treatment in time.[15-17] One might therefore hypothesize that the presence of depressive symptoms may limit the appropriate response to deterioration and increase delay times**.** To our knowledge, no previous studies have examined the relationship between delay and depressive symptoms in HF patients. It is also not known how consulting behaviour is related to delay and to depressive symptoms. The aim of the present study was, therefore, to evaluate whether depressive symptoms are associated with the duration of the delay between the onset of symptoms of worsening HF and hospitalization and to examine how consulting behaviour correlates with depressive symptoms and delay in HF patients.

Methods

Patient population

Data from the index hospitalization of the COACH (Coordinating study evaluating Outcomes of Advising and Counselling in HF patients) study were used for this analysis. The COACH study was a multicenter, randomized trial designed to compare basic support and intensive support to standard treatment in patients with HF. The design and main results of the study have been described in detail before.[18,19] In brief, during a period of 28 months (October 2002-February 2005), all patients aged >18 years admitted to the hospital, with symptoms of HF [New York Heart Association (NYHA) functional classification II-IV] and evidence of structural underlying heart disease, were eligible for recruitment. Major exclusion criteria were concurrent inclusion in another study or HF clinic, inability to complete questionnaires, invasive procedure or cardiac surgery within 6 months, or planned within 3 months, ongoing evaluation for heart transplantation, and inability or unwillingness to give informed consent. The COACH study was approved by the Medical Ethical Committee of the University Medical Centre of Groningen in compliance with the Declaration of Helsinki and all patients provided written informed consent.

Measurements

Demographic and clinical characteristics were assessed by chart review. Data on delay (by a specific question on the time between worsening HF symptoms and hospital admission), depressive symptoms, and consulting behaviour were collected by interview and chart review when patients were stabilized. Patients were also asked if they had experienced HF symptoms during the last month such as dyspnoea, fatigue, oedema and cough, in yes/no format.

Assessments of depressive symptoms, delay, and consulting behaviour

Depressive symptoms were assessed using the Centre for Epidemiological Studies Depression- Scale (CES-D).[20] This 20-item self-report questionnaire is designed to measure depressive symptoms in the general population and in the medically ill.[20,21] The questionnaire is also used in patients with HF.[9] A total sum score is calculated (0-60), with higher scores indicating more depressive symptoms. A cut-off score of 16, which is generally used to define patients at risk for clinical depression, was used to distinguish between HF patients with depressive symptoms (CES-D $\geq$ 16) and HF patients without depressive symptoms (CES-D <16). The CES-D has limited somatic items compared with

other measurement instruments so it can adequately distinguish between somatic complaints attributable to HF and to symptoms of mood disorder.[10]

Delay was defined as the time between the date and time of HF symptom onset and the date and time of admission to the hospital. Data on delay were collected retrospectively in an interview performed by well-trained independent data-collectors at the same time the questionnaires on depressive symptoms and self-care behaviour were completed. The specific question on delay was 'Can you indicate the time between worsening HF symptoms and the date and time of admission to the hospital as accurate as possible in days, hours and minutes.' Consulting behaviour was measured with one of the subscales of the 9-item European Heart Failure Self-care Behaviour Scale (EHFScB-9).[22] The items are rated on a 5-point scale between 1 (I completely agree) and 5 (I completely disagree). The EHFScB-9 (range 0-45) is found to be a reliable and valid scale to measure self-care behaviour. Both the total EHFScB-9 and its subscale 'consulting behaviour' were used. The consulting behaviour subscale consists of four items, (range 0-20) reflecting if patients will consult a health-care provider when HF symptoms worsen (e.g. 'If shortness of breath increases I contact my doctor or a nurse.')[22] Higher scores indicate that a patient has less consulting behaviour.

Statistical analysis

Data from all patients who had a valid measurement on CES-D (n = 958) were used for the analyses. Categorical variables are presented as numbers and percentages and were analysed using the χ^2 test. Continuous variables were analysed with Student's *t*-test or Mann-Whitney U-test, depending on the distribution of normality, and they are presented as mean and standard deviation or median value and interquartile range. A logistic regression analysis (backward stepwise) was performed to evaluate a possible independent association between depressive symptoms and the delay between symptom onset and hospital admission (hereafter described as 'delay'). Since no criteria for delay time exist, the dependent variable was 'longer delay' and was defined as 72 h or longer, which was the median delay time in this population. The same definition was used in another study of delay in patients with HF.[3] Adjustments were made for those variables in Table 1 that had a significant (P <0.05) association with delay: age, NYHA functional class at admission, atrial fibrillation, ischemic heart disease (IHD), dyspnoea, oedema, consulting behaviour, and depressive symptoms. The final logistic regression model demonstrated no multi-colinearity problems according to the variance inflation factor (<10) or the tolerance test (>0.2). No case had any substantial influence on the logistic regression analysis according

to Cook's distance (<1.0). Spearman's rank correlation analysis was performed to evaluate the relationships between depressive symptoms, consulting behaviour, and delay. A *P*-value of <0.05 was considered significant. SPSS 16.0 statistical software was used for the statistical analyses.

Results

Characteristics

Of all 1023 patients who were included in the COACH study, 958 (94%) had a valid measurement on the CES-D and were analysed in the present substudy. There were no significant differences between the demographics of patients who participated in this substudy and the total COACH population. Those who were not included in this substudy (n = 65) had significantly less median hours of delay compared with those who participated (49 vs. 73 h, *P* =0.03).

Patient characteristics and their associations with delay are shown in Table 1. The mean age of the patients was 71 years, 63% were male, and most of the patients had an ischaemic aetiology of HF. Mean left ventricular ejection fraction (LVEF) was 0.34 and 61% had LVEF <0.40. Almost 70% of the patients were hospitalized for HF for the first time. Angiotensin converting enzyme-inhibiters (ACE-I) or angiotensin receptor blockers (ARB), beta-blockers, and diuretics were prescribed in 61% (n = 586), 46% (n = 443) and 75% (n = 721) of the patients, respectively. In total, 94% of the patients reported symptoms of dyspnoea and 86% reported fatigue. Three hundred and seventy-seven patients (39%) reported depressive symptoms (CES-D ≥ 16) (Table 1).

Delay and associated factors

The minimum reported delay was 0 h, whereas the maximum delay was 5832 h (243 days or ~8 months). The median delay time was 72 h (3 days). Patients in the first quartile of delay were admitted to the hospital within 3 h, whereas those in the fourth quartile delayed for at least 338 h, or 14 days (Table 1). Decreased time of delay (<72 h) was associated with higher age, IHD, and prescription of ACE-I/ARB. Increased delay time (≥72 h) was associated with lower NYHA functional class at admission, atrial fibrillation, dyspnoea, fatigue, oedema, consulting behaviour, and depressive symptoms. Patients who had a long delay time (≥ 72 h) reported significantly more dyspnoea at rest, orthopnoea, and dyspnoea during exertion. They also reported more ankle oedema (Table 2).

Table 1. Patient characteristics and their associations with more or less than 72 h of delay				
Variables	**All**	**Delay ≥72 h**	**Delay <72 h**	***P*-value**
	n = 958	**n = 514**	**n = 444**	
Demographics				
Age (years), mean ± SD	71 ± 11	69 ± 11	72 ± 11	<0.001
Male gender, % (n)	63% (604)	65% (331)	62% (273)	0.35
Living with someone, % (n)	60% (582)	63% (320)	59% (262)	0.27
Medical history				
Asthma/COPD, % (n)	29% (274)	29% (149)	28% (125)	0.77
Diabetes, % (n)	28% (266)	26% (133)	30% (133)	0.16
Hypertension, % (n)	43% (416)	44% (227)	43% (189)	0.62
TIA/stroke, % (n)	16% (154)	16% (81)	16% (73)	0.77
Atrial fibrillation, % (n)	44% (422)	48% (244)	40% (178)	0.022
IHD, % (n)	49% (468)	44% (226)	54% (242)	0.001
Renal disease, % (n)	4% (74)	8% (43)	7% (31)	0.47
Haemoglobin (mmol/L), mean ± SD	8.2 ± 1.2	8.2 ± 1.2	8.2 ± 1.2	0.88
HF status				
BNP (pg/dl), median (IQR) (discharge)	454 (198-876)	494 (218-934)	412 (178-835)	0.065
LVEF (%), mean ± SD	34 ± 14	33 ± 15	35 ± 14	0.094
LVEF<40%, % (n)	61% (623)	68% (318)	65% (262)	0.27
NYHA class, II and III/IV, % (n)	5% (48)/95% (902)	6% (33)/94% (476)	3% (15)/97% (426)	0.03

Table 1 (Continued). Patient characteristics and their associations with more or less than 72 h of delay				
Variables	**All**	**Delay ≥72 h**	**Delay <72 h**	***P*-value**
	n = 958	**n = 514**	**n = 444**	
Symptoms of HF at admission				
Dyspnoea, % (n)	94% (900)	98% (502)	91% (398)	<0.001
Fatigue, % (n)	86% (821)	93% (478)	78% (343)	<0.001
Oedema, % (n)	64% (609)	71% (364)	55% (245)	<0.001
Cough, % (n)	67% (640)	69% (356)	64% (245)	0.10
Previous HF admissions				
≥1, yes, % (n)	32% (311)	30% (156)	35% (155)	0.13
Delay				
Hours between HF symptoms and hospital admission, median (IQR)	72 (3-338)	336 (168-672)	2 (1-18)	<0.001
EHFScB-9				
EHFScB-9 total score, mean ± SD	34.0 ± 5.5	34.4 ± 5.5	33.9 ± 5.4	0.12
Consulting behaviour, mean ± SD	8.0 ± 3.3	8.1 ± 3.2	8.6 ± 3.2	0.015
Depressive symptoms				
CES-D total score, mean ± SD	15 ± 13	16 ± 11	14 ± 10	<0.001
CES-D≥16, % (n)	39% (377)	44% (228)	34% (149)	0.001

BNP *brain natriuretic peptide;* CES-D *Centre for Epidemiological Studies-Depression Scale;* COPD *chronic obstructive pulmonary disease;* EHFScB-9 *European Heart Failure Self-care Behaviour Scale;* HF *heart failure;* IHD *Ischaemic heart disease;* IQR *inter-quartile range;* LVEF *left ventricular ejection fraction;* NYHA *New York Heart Association classification;* TIA *transient ischaemic attack.*

Table 2. Symptoms of dyspnoea and oedema in patients with ≥72 h or < 72 h delay			
	Delay ≥72 h n = 514	**Delay <72 h n = 444**	***P*-value**
Dyspnoea at rest, % (n)	37% (354)	24% (233)	0.001
Orthopnoea, % (n)	40% (383)	26% (252)	0.001
Dyspnoea during exertion, % (n)	52% (494)	40% (381)	0.001
Ankle oedema on waking up, % (n)	28% (270)	17% (161)	0.001
Ankle oedema during the course of the day, % (n)	36% (347)	25% (236)	0.001

Delay and depressive symptoms

In patients with depressive symptoms, the median delay time was 120 h. This was significantly higher (P =0.001) than the median delay time of 54 h reported by patients without depressive symptoms.

To examine if the presence of depressive symptoms was independently associated with delay, logistic regression analyses were performed using delay ≥72 h as the dependent variable. Adjustments were made for age, NYHA functional class at admission; atrial fibrillation, IHD, dyspnoea, oedema, consulting behaviour, and depressive symptoms. Since fatigue is also a primary symptom of depression,[23] it was not included in the logistic regression analysis. Patients with depressive symptoms had almost 1.5 times higher risk of increased delay time independent of the above-mentioned variables (P =0.008) (Table 3). This association was of the same magnitude as atrial fibrillation and oedema. Dyspnoea was the most powerful predictor for longer delay and was associated with a more than 4 times increased risk for a longer delay. Ischaemic heart disease and higher age were independently associated with lower likelihood of longer delay.

Delay, consulting behaviour, and depressive symptoms

Total self-care behaviour was weakly related to depressive symptoms (r = 0.08, P =0.015), patients with higher self-care scores (i.e. lower self-care) were more depressed. However, there was no significant association between total self-care behaviour and delay. In contrast, specific consulting behaviour was weakly correlated to delay (r = 0.07, P =0.03), and we found that better self-reported consulting behaviour (low scores) was actually weakly correlated to longer delay. Consulting behaviour was not significantly correlated to depressive symptoms.

Table 3. Independent predictors of ≥72 h delay between HF symptoms and hospital admission

	B (SE)	**Odds ratio (95% CI)**	***P-value***
Depressive symptoms (CES-D≥16)	0.37 (0.14)	1.45 (1.10-1.90)	0.008
Age, per year increase	-0.22 (0.006)	0.98 (0.97-0.99)	0.001
Atrial fibrillation	0.30 (0.14)	1.30 (1.01-1.70)	0.045
IHD	-0.32 (0.14)	0.72 (0.56-0.97)	0.023
NYHA II vs. III/IV	-0.89 (0.34)	0.41 (0.21-0.81)	0.01
Dyspnoea	1.50 (0.38)	4.60 (2.10-9.80)	<0.001
Oedema	0.68 (0.14)	1.97 (1.48-2.60)	<0.001

CES-D *Centre for Epidemiologic Studies Depression Scale;* CI *confidence interval;* IHD *ischaemic heart disease;* NYHA *New York Heart Association functional class.*

Discussion

This is the first large-scale report on the relationship between depressive symptoms, consulting behaviour, and delay in patients with HF. Patients with depressive symptoms had a significantly longer delay from HF symptom onset to hospital admission compared with patients without depressive symptoms. Depressive symptoms independently increased the risk of delay of more than 72 h by almost 50%. In a recent study of patients with ACS, depressive symptoms increased the risk of delay comparable with our study.[24] Depressive patients might have inadequate coping strategies, resulting in avoidance, disengagement, and self-blame.[25] This prevents the patients from having a realistic interpretation of their situation, can make them feel hopeless and make them fail to attribute their symptoms to HF.[15] Personality traits may also play a role, in that patients with shorter delay have more dynamic responses to changes in symptoms and patients with longer delay have a more static response because they have a constant perception of suffering from severe symptoms.[26] Symptoms of HF and depression are to some extent similar and can lead to an overestimation of depression in patients with HF, which could suggest that the presence of depressive symptoms in HF is only a reflection of symptom severity. However, it is known that patients with chronic diseases and HF do not have more somatic symptoms compared with patients with primary depression.[27,28]

The delay between the onset of symptom deterioration and hospitalization in this study was on average 3 days, which is comparable with other studies examining delay in

patients with HF.[3,4,29] This rate is higher than the median pre-hospital delay of 2.5-3 h reported for patients with myocardial infarction or unstable angina.[30] Differences in symptom presentation and onset could be possible a reasons for these differences. In our study as well as in other studies, dyspnoea was the most common symptom on hospital admissions due to HF [3,5,29] However, both dyspnoea and oedema were associated with an increased delay of more than 72 h. This unexpected finding may be explained by the fact that HF patients often have a gradual increase in symptoms over days or weeks. Thus, they often do not realise that their symptoms could be signs of a serious deterioration and therefore the increase in symptoms might not induce a feeling of fear and anxiety and does not urge the patient to seek help. Jurgens *et al.*[4] reported that low anxiety in HF patients was associated to longer duration of delay. In contrast, other studies have reported that chest pain in HF patients is associated with decreased delay.[3,4,29] In our study, information on chest pain was not collected; however, we found that a history of IHD was related to shorter delay. People might be more likely to seek medical care if they believe that their symptoms might be related to a heart attack.[31] Heart failure patients may delay longer due to the fact that typical symptoms and signs in HF are familiar to them and are not perceived as being acute or life threatening, and therefore do not cause anxiety. This could explain why a lower NYHA class is related to longer delay.

We hypothesized that patients with depressive symptoms have lower consulting behaviour as well as lower self-care behaviour in general. Previous studies on the association between depressive symptoms and self-care behaviour are inconclusive.[17,32-34] In the present study, depressive symptoms were not strongly associated with consulting behaviour. Maladaptive coping strategies are common in HF patients with depressive symptoms.[25] Depressed HF patients who recognize symptom deterioration may not have the energy or drive to contact health-care providers. A recent study reported that inaccurate beliefs, such as 'HF cannot be influenced by my behaviour', were found to be associated with depression in HF patients, although the patients knew that their disease was a serious condition.[35] In another study on self-care and depression in HF patients, lower self-care was associated with minor but not major depression.[36] Unfortunately, we could not study this relationship in our study because the CES-D questionnaire is not a diagnostic instrument so it cannot distinguish between minor and major depression. Also in addition, we did not find a strong relationship between consulting behaviour and delay. Some patients may even report that they plan to seek help from a health-care professional in case of increasing symptoms but do not translate this into help-seeking behaviour at the time of deterioration. This confirms that patients' words do not always fit their actions, and educational strategies

should be focused on acquiring skills and discussing very specific actions which patients need to undertake.[37-38] One important factor could be the confidence that HF patients have about what to do and when to take action. Schweitzer *et al.*[34] reported that trust in one's ability to perform self-care behaviour was significantly associated with adherence in HF patients, whereas the presence of depressive symptoms was not. On the other hand, depressive symptoms have been found to have an impact on self-efficacy in patients with HF.[39] To obtain more insight into the mechanisms underlying the relationship between delay and depression, future studies should focus on the relationship between depressive symptoms, self-confidence, and delay.

This study is limited by the fact that we used a retrospective self-assessed 'time' between deterioration and admission to hospital. In addition, symptoms may have varied considerably in severity between patients, which is probably an important determinant of the time delay between deterioration and hospitalization. This may have underestimated the delay time for some patients and overestimated it for others. However, in research into delay times one often has to depend on self-assessment data from patients or proxies. Another limitation is that we do not have any data on other reasons for delay not caused by the patients, such as waiting time for admission to the hospital. The cross-sectional nature of the design precludes any attempt to establish the direction of causality. Despite these limitations, we think that this study, based on a large sample of 985 patients is of major interest since few, if any, studies have examined the association between depressive symptoms, consulting behaviour and delay, in patients with HF.

In conclusion, this study shows that patients with depressive symptoms delayed longer between HF symptom onset and hospital admission compared with patients without depressive symptoms. Consulting behaviour was weakly associated with depressive symptoms and delay. Screening for and treating depression could be possible health care actions, but may not automatically decrease delay times. Interventions such as patient education aimed at improving consulting behaviour cannot be expected to decrease delay at the same time. The long-term consequences of increased delay in patients with HF are unknown and more studies are needed to unravel the underlying mechanisms.

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Conflict of interest:
none declared.

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Chapter 7

Factors associated with patient delay in seeking care after worsening symptoms in heart failure patients

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Abstract

Background

To receive optimal treatment and care, it is essential that heart failure (HF) patients react adequately to worsening symptoms and contact a health care provider early. This specific 'patient delay' is an important part of the total delay time. The purpose of this study was to assess patient delay and its associated variables in HF patients.

Methods and Results

In this cross-sectional study, data of 911 hospitalized HF patients from 17 Dutch hospitals (mean age 71 ± 12 years, 62% male, left ventricular ejection fraction 34 ± 15%) were analyzed. During the index hospitalization, patient delay and HF symptoms were assessed by interview. Patients completed questionnaires on depressive symptoms, knowledge, and compliance. Clinical and demographic data were collected from medical charts and interviews by an independent data collector. Logistic regression analysis was performed to examine independent associations with patient delay. Median patient delay was 48 hours; 296 patients reported short delay (<12 h) and 341 long delay (≥168 h). A history of myocardial infarction (MI) (odds ratio [OR] 0.49, 95% confidence interval [CI] 0.34-0.71) or stroke (OR 0.43 95% CI 0.24-.076) was independently associated with short patient delay. Male gender, more HF knowledge, and more HF symptoms were associated with long patient delay. No differences were found between patients with and without a history of HF.

Conclusions

Patients with a history of a life-threatening event (MI or stroke) had a shorter delay than patients without such an event. Patients without a life-threatening event might need to be educated on the recognition and need for appropriate action in a different way than those with an acute threatening previous experience.

Introduction

Heart failure (HF) is one of the main causes of hospitalization in the adult population.[1] Adequate self-care behaviour is an important factor reducing the risk of readmissions due to worsening of HF.[2] Along with compliance with medication, diet, and exercise, self-care behavior consists of adequate recognition of deterioration and taking relevant actions in case of worsening HF symptoms.[3] The early recognition of symptoms of HF is important, because they might be warning signs of further deterioration.[1] Long pre-hospital delay after onset of acute coronary syndrome (ACS) negatively affects the patient's prognosis.[4,5] In HF patients, many admissions could have been prevented if patients had sought medical care in an earlier stage of worsening symptoms.[2,6-9] However, long pre-hospital delay times are common in HF patients.[6,7,10]

In studying delay in cardiovascular patients, it is important to distinguish between 'patient delay' (time from worsening symptoms to actually contacting a health care provider) and 'transportation delay' (time from contacting a health care provider to arrival at the hospital). Pre-hospital delay therefore can be defined as the combination of patient and transportation delay (Figure 1).[11]

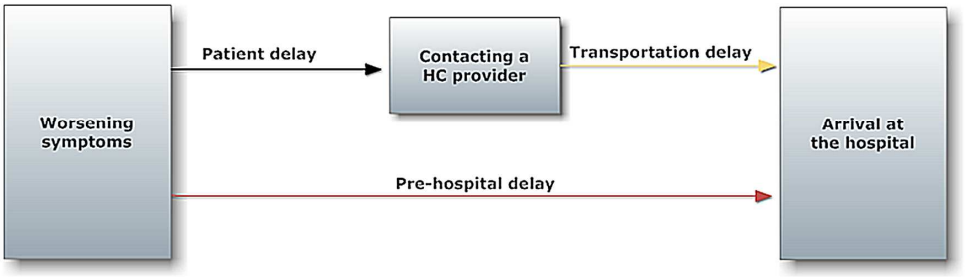

Figure 1. Time schedule of patient-, transportation- and pre-hospital delay

The importance of timely seeking care in the ACS population is recognized, and delay in this population has been well established.[4,5,11-14] In ACS, symptoms such as angina are often sudden and interpreted by patients as threatening, resulting in seeking medical care early.[5,11] In contrast, the most common symptoms of worsening HF (dyspnea and fatigue)[2,6,8,15] often have a gradual pattern of worsening. Therefore, many HF patients do

not seek medical care but wait for a decline in symptoms.[10,15] Patient delay can be due to a failure to routinely monitor symptoms or to the inability to recognize and interpret symptoms when they occur.[16] Elderly patients may neglect early symptoms such as fatigue and dyspnea by attributing them to aging or other illnesses, thereby interpreting them as less threatening and non-acute,[17] which can result in a longer delay.

Although delay in HF patients has been studied previously,[6-10] those studies actually assessed pre-hospital delay (Figure 1). However, little is known on patient delay defined as the time from worsening symptoms to actually contacting a health care provider, which reflects the patient's own action in seeking care. More insight into this process can help to identify those who are at risk for long patient delay. The relationship between a history of HF and delay has been assessed,[6-10] but factors related to delay in those patients has not. Therefore, the aims of the present study were: 1) to examine patient delay time in HF patients; 2) to assess which variables are associated with patient delay in HF patients; and 3) to assess which variables are associated with patient delay in patients with a history of HF.

Methods

This descriptive, cross-sectional study on patient delay is a secondary analysis of COACH (Coordinating study evaluating Outcomes of Advising and Counseling in Heart failure). COACH was a randomized, multicenter, controlled study in which 1023 hospitalized HF patients were included between November 2002 and February 2005 (registered at trialregister.nl, no. NTC98675639).[18,19] Patients were included in the study during an admission for HF (New York Heart Association [NYHA] functional class II-IV), with HF as the primary diagnosis confirmed by the cardiologist, and they were ≥18 years of age. Exclusion criteria were participation in another study, a planned or recent invasive cardiac intervention, and inability to complete questionnaires. The main objective of COACH was to evaluate the effect of education and counseling by an HF nurse on clinical outcome. The study complied with the Declaration of Helsinki and the Medical Ethics Committee granted approval for the protocol. Each of the patients provided written informed consent and was examined during a fixed period of 18 months after discharge from the hospital. In the present study, patients were excluded from analyses when they had a patient delay time of 0 hours and, at the same time, were in NYHA-class IV during admission. These patients had an acute episode of HF, resulting in calling a health care provider immediately (i.e. patient delay 0 hours) owing to this very serious condition. Not calling a health care provider in

this situation is unimaginable, and because the focus of this study was on determinants of patient delay, these specific patients were excluded.

Patient delay, HF symptoms, and HF experience

Patient delay in this study was defined as the time between worsening HF symptoms and calling a health care provider. Patients were asked to indicate the time from worsening HF symptoms as experienced by themselves to the moment they contacted a health care provider (i.e. general practitioner, HF nurse, or emergency department) as accurate as possible in days, hours and minutes. To differentiate between patients who called a health care provider in an early stage ('short delay') and patients who waited for a substantial time to seek care ('long delay'), cutoff scores were formulated based on the 33rd and 66th percentiles of the patient delay time; patients with a short patient delay contacted a health care provider within 12 hours, and patients with a long patient delay waited 168 hours (1 week) or more.

In addition, patients were asked whether they had the following symptoms of HF during the past 4 weeks before hospitalization; swollen ankles/legs (after waking up or during the day), sleeping problems, loss of appetite, fatigue, dyspnea (at rest, lying flat, or on exertion), cough, and dry cough. Data on patient delay time and HF symptoms were collected by a well-trained independent data collector during the index hospitalization. Patients were defined as 'patients with a history of HF' when they had a history of ≥1 previous HF admissions and had HF symptoms for ≥6 months.

Compliance, self-care behaviour, and knowledge

Compliance with the HF regimen was measured with the Revised Heart Failure Compliance Scale.[20] Internal consistency of the instrument was tested using Cronbach α (0.68). For the Dutch version of the scale, two HF nurses experienced in the field of compliance assessed face validity.

Compliance was measured on a 5-point scale (0 = never; 1 = seldom; 2 = half of the time; 3 = mostly; 4 = always). Patients were asked to rate their compliance the past week (medication, sodium-restricted diet, fluid restriction, and exercise), the past month (daily weighing), or the last 3 months (appointment keeping) before index hospitalization. Patients were defined as compliant when they followed the recommendation 'always' or 'mostly'. Regarding daily weighing, patients were compliant when they weighted daily or ≥3 times a week. Patients were considered to be 'overall compliant' when they were compliant with ≥4 of the 6 recommendations.

Self-care behavior was measured with the 12-item European Heart Failure Self-care Behavior Scale (EHFScB), which was found to be a reliable and valid scale to measure self-care behavior.[3] The items are rated on a 5-point scale between 1 (completely agree) and 5 (completely disagree), with lower scores indicating that patients perform more self-care behavior. The EHFScB can be reduced to 9 items (EHFScB-9),[21] representing 2 subscales: 'consulting behaviour' and 'adherence to regimen'. The total score of both subscales was also used for analysis.

Knowledge on HF and the regimen was measured with the Dutch HF Knowledge Scale, which consists of 15 multiple choice items (range 0-15). This scale is a reliable and valid instrument to measure knowledge on HF in general, symptom recognition, and HF treatment.[22] All questionnaires were completed at baseline during the index hospitalization.

Clinical and demographic variables

At baseline, clinical variables (e.g. medical history, comorbid conditions such as myocardial infarction [MI] or stroke) were assessed from the patients' medical records; demographic variables were collected by using interviews by an independent data collector. The Centre for Epidemiological Studies-Depression Scale (CES-D) was used to measure depressive symptoms.[23] This scale consists of 20 items and measures the presence of depressive feelings and behaviors ranging from 0 ('rarely or none of the time') to 3 ('most or all of the time'). The total score ranges from 0 to 60 and a score of $\geq$ 16 is an indication for the presence of depressive symptoms.

Statistical analysis

Descriptive statistics were used to characterize the study population. Differences between patients with short and long patient delay were tested with chi-square tests or Fisher exact tests for dichotomous variables and Mann-Whitney tests for continuous variables. A *P*-value of <.05 (2 tailed) was considered to be statistically significant. Logistic regression analysis was performed to assess which characteristics and clinical variables were independently associated with patient delay. Long patient delay ($\geq$ 1 week) was used as the dependent variable. Based on theoretical assumptions and an univariable *P*-value of <.05, the following variables were inserted in the regression model by using backward methods: age, gender, NYHA functional class at admission, depressive symptoms, history of MI, diabetes, or stroke, HF knowledge, all HF symptoms except from (dry) cough, and the total amount of symptoms.

Patients with a history of HF were diagnosed with HF before the index hospitalization, assuming that these specific patients were already treated according to guidelines (including advice on the HF regimen, e.g. sodium restriction, fluid restriction, daily weighing). Therefore, differences in compliance and self-care behavior were only assessed in those patients with a history of HF.

Logistic regression analysis was also performed to assess which variables were independently associated with long patient delay in patients with a history of HF. Based on theoretical assumptions and an univariable *P*-value of <.05, the following variables were inserted in the regression model: age, gender, educational level, diabetes, HF knowledge, swollen ankles (after waking up and during the day), loss of appetite, fatigue, dyspnea at rest, and total amount of symptoms. SPSS 16.0 statistical software (Chicago, IL) was used for statistical analyses.

Results

Characteristics of the study population

A total of 1023 patients participated in COACH. Of these patients, 112 had a patient delay time of 0 hours and, at the same time, were in NYHA functional class IV at admission and were therefore excluded from analyses. Those patients did not significantly differ in age, gender, and left ventricular ejection fraction (LVEF) from the 911 patients included in this substudy. The mean age of the study population (n = 911) was 71 ± 12 years, and 62% were male. The mean length of HF symptoms was 32 ± 54 months and the mean LVEF was 34 ± 15%. Most patients were in NYHA functional class III (57%) or IV (37%) during admission, and 40% of the patients had depressive symptoms (Table 1). Based on the 33rd and 66th percentiles of patient delay time, 296 (33%) had a patient delay <12 hours and 341 patients (37%) waited for ≥1 week before they contacted a health care provider. In this study, both patients with preserved (n = 279) and reduced (n = 552) ejection fraction were included. However, no significant difference in delay time was found between these 2 groups. The 2 most reported HF symptoms in the study population were dyspnea on exertion (92%) and fatigue (88%).

Patient delay and associated variables

The median patient delay time was 48 hours in this study population. Patients with a short delay more often had a history of MI, diabetes, or stroke. Patients with a long patient delay were significantly younger, were more often male, had a higher educational level, and more

often reported depressive symptoms compared with those with short patient delay. These patients were also more often classified as NYHA functional class IV at admission and had more HF knowledge and reported more HF symptoms than those with short patient delay time (Table 1). Except from (dry) cough, HF symptoms significantly occurred more often in patients with a long patient delay.

In a multivariable analysis, a history of MI (odds ratio [OR] 0.49, 95% confidence interval [CI] 0.34-0.71) or stroke (OR 0.43, 95% CI 0.24-0.76) was inversely associated with long patient delay time, indicating that patients with a MI or stroke contacted a health care provider at an earlier stage. Male gender (OR 1.58, 95% CI 1.09-2.29) and more HF knowledge (OR 1.10, 95% CI 1.01-1.18) were also independently associated with long patient delay. The following HF symptoms were associated with long patient delay: swollen ankles (OR 1.50, 95% CI 1.05-2.15), loss of appetite (OR 1.77, 95% CI 1.23-2.56), fatigue (OR 2.93, 95% CI 1.60-5.38), dyspnea at rest (OR 1.58, 95% CI 1.09-2.30), and dyspnea during exercise (OR 2.58, 95% CI 1.19-5.57) (Table 2).

Patient delay in patients with a history of HF and associated variables

To specifically examine the role of experience with chronic HF and earlier HF readmissions on patient delay, the same uni- and multivariable analyses were conducted in a subgroup of patients with a history of HF (i.e. HF symptoms ≥ 6 months and a previous HF admission). To assess the additional role of self-care behavior and compliance, these variables were added in the univariable analysis with 267 (29%) patients with a history of HF.

Patients with a history of HF had the same median patient delay. Also a similar percentage of these patients had short (< 12 hours; 31%; n = 94) and long (≥1 week; 31%; n = 83) patient delay before calling a health care provider. The same univariable differences were found for age, gender, educational level, diabetes, HF knowledge, and HF symptoms as reported for the total group. In contrast to data of the total group, in patients with a history of HF, no differences between patients with short versus long delay in MI, stroke, NYHA functional class, and depressive symptoms were found (Table 3).

No differences were found in self-care behavior between patients with a history of HF with short versus long patient delay. Regarding the care-seeking behavior scale, patients with long delay reported that they would contact a health care provider in case of worsening symptoms with the same magnitude of patients with a short delay (8.5 vs. 8.7, ns).

No differences in compliance between patients with a short or long patient delay were found, neither in ‘overall compliance’ (~75% in both groups) nor in compliance with the

Table 1. Characteristics of the study population and differences between patients with short and long patient delay

	All patients (n = 911)	**Delay <12 h (n = 296)**	**Delay ≥1 wk (n = 341)**	***P*-Value**
Demographics				
Age (years), mean ± SD	71 ± 12	73 ± 11	70 ± 11	<.01
Male gender, % (n)	62% (565)	57% (169)	67% (227)	.01
Living with a partner, % (n)	61% (550)	56% (162)	63% (215)	.07
High educational level, % (n)	10% (90)	8% (23)	13% (44)	.04
Clinical variables				
LVEF (%), mean ± SD	34 ± 15	35 ± 15	34 ± 14	.55
NYHA class (Admission), % (n)				<.01
- II	6% (52)	4% (12)	6% (20)	
- III	57% (517)	67% (196)	54% (182)	
- IV	37% (333)	29% (85)	40% (135)	
Length of HF (months), mean ± SD	32 ± 54	31 ± 47	29 ± 52	.41
Previous HF admission, % (n)	32% (291)	33% (98)	27% (92)	.09
Depressive symptoms, % (n)	40% (345)	35% (95)	45% (144)	.01
History of MI, % (n)	42% (378)	50% (148)	33% (114)	<.01
HF symptoms, mean ± SD	6.5 ± 2.2	5.6 ± 2.3	6.9 ± 1.9	<.01
Smoking, % (n)	16% (140)	16% (44)	16% (54)	.89
Alcohol (units/day), mean ± SD	0.7 ± 1.4	0.7 ± 1.3	0.8 ± 1.4	.17

Table 1 (Continued). Characteristics of the study population and differences between patients with short and long patient delay

	All patients (n = 911)	**Delay <12 h (n = 296)**	**Delay ≥1 wk (n = 341)**	***P*-Value**
Etiology of HF				
CAD, % (n)	43% (387)	50% (147)	35% (119)	<.01
Hypertension, % (n)	14% (125)	15% (45)	15% (51)	.93
Cardiomyopathy, % (n)	24% (217)	19% (55)	28% (94)	<.01
Comorbidities				
Diabetes. % (n)	28% (252)	30% (89)	23% (77)	.03
COPD, % (n)	26% (238)	26% (78)	26% (89)	.94
Stroke, % (n)	10% (93)	15% (44)	8% (27)	<.01
HF knowledge				
Total score, mean ± SD	11.6 ± 2.3	10.7 ± 2.3	11.2 ± 2.3	<.01

CAD *coronary artery disease;* COPD *chronic obstructive pulmonary disease;* HF *heart failure;* LVEF *left ventricular ejection fraction;* MI *myocardial infarction;* NYHA *New York Heart Association.*

separate components of the HF regimen. Compliance with daily weighing, a component of the HF regimen related to symptom monitoring, was low in both groups (32% and 34%).

In a multivariable analysis, it was found that patients with a history of HF with more HF knowledge (OR 1.17, 95% CI 1.01-1.36) and those who were male (OR 2.22, 95% CI 1.11-4.44) were more likely to delay. Furthermore, the total amount of HF symptoms was independently associated with long patient delay, indicating that patients with a history of HF and a long delay in seeking care presented with more HF symptoms at the hospital compared with those with a short patient delay.

Table 2. Variables independently associated with long patient delay in HF patients (n = 598)

Variable	Odds ratio (95% CI)	*P*-value
Male gender	1.58 (1.09-2.29)	.02
MI	0.49 (0.34-0.71)	<.01
Stroke	0.43 (0.24-0.76)	<.01
HF Knowledge	1.09 (1.01-1.18)	.03
Swollen ankles (after waking up)	1.50 (1.05-2.15)	.03
Loss of appetite	1.77 (1.23-2.56)	<.01
Fatigue	2.93 (1.60-5.38)	<.01
Dyspnea at rest	1.58 (1.09-2.30)	.02
Dyspnea on exertion	2.58 (1.19-5.57)	.02

CI *confidence interval;* HF *heart failure;* MI *myocardial infarction.*

Discussion

Although delay in HF patients was assessed in previous studies, those studies assessed the time from worsening symptoms to arrival at the hospital. The scope of the present study was on patient delay, reflecting the time from worsening symptoms to actually contacting a health care provider**.** The most important findings of this study were that a history of MI or stroke was independently associated with short patient delay. We also found that male gender, more HF knowledge, and the presence of swollen ankles, loss of appetite, fatigue, or dyspnea were independently associated with long patient delay. Patients with a history of MI or stroke had a shorter patient delay time than those without these events, which was also found in studies on delay in patients with ACS.[13,14]

Table 3. Differences between patients with a history of HF with short and long patient delay

	Delay <12 h (n = 92)	**Delay ≥1 wk (n = 83)**	***P*-Value**
Demographics			
Age (years), mean ± SD	74 ± 11	71 ± 10	<0.01
Male gender, % (n)	52% (48)	71% (59)	0.01
Living with a partner, % (n)	55% (47)	60% (49)	0.50
High educational level, % (n)	7% (6)	18% (15)	0.02
Clinical variables			
LVEF (%), mean ± SD	36 ± 15	36 ± 14	0.86
NYHA functional class (Admission), % (n)			0.10
- II	8% (7)	7% (6)	
- III	66% (60)	54% (44)	
- IV	26% (24)	38% (31)	
Length of HF (months), mean ± SD	60 ± 45	76 ± 70	0.17
Previous HF admissions, mean ± SD	1.6 ± 1.0	1.8 ± 1.5	0.62
Depressive symptoms, % (n)	43% (36)	44% (35)	0.96
History of MI, % (n)	57% (52)	45% (37)	0.12
HF symptoms, mean ± SD	5.8 ± 2.4	7.0 ± 1.9	0.03
Smoking, % (n)	15% (13)	12% (10)	0.60
Alcohol (units/day), mean ± SD	0.6 ± 1.6	0.8 ± 1.5	0.36
Etiology of HF			
CAD, % (n)	53% (49)	51% (42)	0.73
Hypertension, % (n)	10% (9)	11% (9)	0.82
Cardiomyopathy, % (n)	20% (18)	25% (21)	0.36
Comorbidities			
Diabetes, % (n)	41% (38)	24% (20)	0.02
COPD, % (n)	37% (34)	33% (27)	0.54
Stroke, % (n)	16% (15)	10% (8)	0.19
HF knowledge			
Total score, mean ± SD	10.5 ± 2.3	11.4 ± 2.2	0.01

CAD *coronary artery disease;* COPD *chronic obstructive pulmonary disease;* HF *heart failure;* LVEF *left ventricular ejection fraction;* MI *myocardial infarction;* NYHA *New York Heart Association.*

Because patient delay reflects the patient's own decision process, a previous cardiovascular, life-threatening event might have led to a higher symptom awareness, more adequate symptom evaluation and quicker decision making. However, this relationship was not found in a study by Goldberg et al.[9] This could be due to a different definition of delay, the retrospective study design or the large amount of missing data (56%) in the study sample. Furthermore, a history of a previous HF admission was not associated with short patient delay in our study, indicating that patients do not seem to benefit from their earlier experience with HF.[7]

HF knowledge has an association with better self-care behaviors, such as compliance with the regimen.[24,25] In the present study, a longer patient delay was independently associated with more HF knowledge in all patients, as well in those with a history of HF. This result is quite remarkable, because one could expect that patients with more HF knowledge, including knowledge of HF symptoms, would seek care earlier.[25] Patients with more HF knowledge might try to manage the worsening symptoms themselves by, e.g., taking extra diuretics or adjusting their fluid or salt intake[8] instead of calling a health care provider. However, it is worrisome that performing self-care behaviors is often challenging in HF patients; besides adequate self-care behaviors, also insufficient or counterproductive behaviors, such as drinking more water or taking medications other than prescribed, are performed.[2] This stresses the importance of providing education and information on adequate self-care behaviors in case of worsening symptoms.

Another explanation is that these patients do have enough general HF knowledge, but they lack the specific knowledge to recognize or to adequately anticipate worsening HF symptoms. Patients often have insufficient information about recognition, causes, symptoms, management and consequences of HF; therefore, they are not fully prepared to self-manage. Furthermore, it is often difficult for chronic HF patients to differentiate between baseline symptoms and signs of deterioration.[26]

Gender was independently associated with patient delay, which has also been reported in another study [9]; male patients were more likely to delay in seeking care. This result was found for all patients, as well for patients with a history of HF. This was not found in 2 other studies on delay in HF patients.[6,8] In contrast, from the ACS population it is known that female patients more often had long delay in case of onset of MI compared with males.[14] The most important explanations for longer delay in women with ACS were older age, perceiving atypical symptoms, living alone, and additional comorbidities.[14] We did not found these differences in HF patients. Further research on the specific role of gender in delay in HF patients is needed.

In the present study, in patients with a history of HF, no differences in self-care behavior and compliance between patients with a short or long delay were found. Although patients report that they would contact a health care provider in case of worsening symptoms, many patients delay in seeking care when those symptoms actually occur. Three-fourths of the patients with a history of HF were overall compliant with the regimen; however, compliance with daily weighing was low (~ 35%). It is known that many patients fail to monitor their weight or are unaware of the importance of this self-care behavior.[27] Although it is suggested that compliance with recommendations on daily weighing may lead to detecting worsening symptoms in an earlier stage,[28] this aspect of the nonpharmacologic regimen did not affect patient delay time in the present study.

Depressive symptoms have a negative effect on clinical outcome in HF patients[29] and are associated with low self-care behavior.[30] It was also found that patients with depressive symptoms do not benefit regarding mortality and readmission from a disease management program directed at education and counseling.[31] In this study, depressive symptoms were not associated with long patient delay. In contrast, in one of our previous studies which was also based on COACH data, we found an association between depressive symptoms and long delay in HF patients.[32] However, in line with other studies on delay in HF, that previous study also actually assessed pre-hospital delay, which may be one of the explanations for the differences in results regarding the relation between depressive symptoms and delay. Another explanation may be the use of different formulations of cutoff points to differentiate between short and long delay (median versus 33rd and 66th percentiles of the delay time).

In the present study, HF symptoms were independently associated with patient delay. However, from these data it is not clear whether a long delay resulted in more HF symptoms or that some HF symptoms resulted in a longer patient delay. One the one hand, it might be reasonable to assume that early undetected HF symptoms may develop into more severe symptom manifestation. On the other hand, symptoms such as swollen ankles, loss of appetite, and fatigue often have a gradual pattern of worsening and can be perceived as not important or nonthreatening, thus resulting in a longer patient delay, as was also suggested in other studies.[10,15]

One of the limitations of the present study is the use of arbitrary cutoff scores based on the 33rd and 66th percentiles to differentiate between patients with short and long patient delay. However, in the existing literature no standard criterion on short or long delay time has been formulated. Another limitation is that there were no data on the behavior of the patients during the time from worsening symptoms to calling a health care

provider. Further research is needed to assess the patient's own actions and coping strategies in case of worsening symptoms. A final limitation is the cross-sectional design of the study; a prospective design would have been preferable in for establishing direction of causality.

Conclusion and implications

Patients with a history of a serious, life-threatening event, such as MI or stroke, contacted a health care provider earlier in case of worsening HF symptoms, compared with those without such event. More HF knowledge, male gender, and more HF symptoms were also independently associated with long patient delay in all patients and those with a history of HF. Although these results might suggest a profile of HF patients vulnerable to long delay in seeking care after worsening symptoms, further research is needed to obtain more insights on symptom recognition and performed actions from time to worsening symptoms to actually calling a health care provider. To reduce patient delay, patients should be educated on the importance and recognition of worsening symptoms and the importance of care seeking in case of deteriorating HF. Education of patients should stress the importance of recognizing relevant symptoms and taking appropriate action, even if symptoms do not seem acute or life-threatening to them.

Disclosures

None

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Chapter 8

General discussion

General discussion

Heart failure (HF) is a malignant condition with a poor prognosis. However, adequate self-care behaviour is related to a decreased risk of hospitalization and mortality.[1,2] To obtain more insights in self-care behaviour in terms of compliance and delay and its associated variables in HF patients, we conducted several substudies in the Dutch Coordinating study evaluating Outcomes on Advising and Counselling in Heart failure (COACH).[3,4]

The first aim of the thesis was to assess compliance with medication. Our study using the Medication Event Monitoring System (MEMS) demonstrated that, although all patients reported 100% compliance, 1 out of 4 patients actually did not take their medication as prescribed. Moreover, these patients may also had an increased risk for adverse outcomes, since compliance was defined using an evidence-based cutpoint. Non-compliant patients were more often prescribed a '2-3 times a day' regimen (instead of 'once a day'), had a shorter history of HF, and had more often depressive symptoms, compared with their compliant counterparts.

Further aims were to assess short-term and long-term compliance with lifestyle recommendations, such as sodium-restricted diet, fluid restriction, daily weighing and exercise recommendations. We found that perceived difficulty and the amount of the prescribed restriction are relevant concepts in compliance with diet and fluid restriction. Higher levels of intrinsic motivation and identified regulation were associated with compliance with exercise recommendations. Compliant patients considered regular physical activity more often as important and found it less difficult to comply with exercise recommendations, compared with non-compliant patients. In our study on long-term compliance, we found that long-term compliance with exercise and daily weighing was lower than compliance with advice on diet and fluid restriction. Lower levels of knowledge on HF and not being offered education and counselling were associated with low compliance with fluid restriction and daily weighing, but not with exercise recommendations. Physical limitations related to older age and comorbidity seem to play a larger role in non-compliance with exercise, than physical limitations related to HF itself.

The final aim of this thesis was to assess delay in seeking care after worsening symptoms (Figure 1) and its associated variables. We found that patients with depressive symptoms had a longer delay from worsening symptoms to hospital admission (i.e. pre-hospital delay). The main finding of our study on patient delay is that patients with a history of a serious, life-threatening event, such as MI or stroke, contacted a health care provider earlier in case of worsening HF symptoms, compared with those without such event.

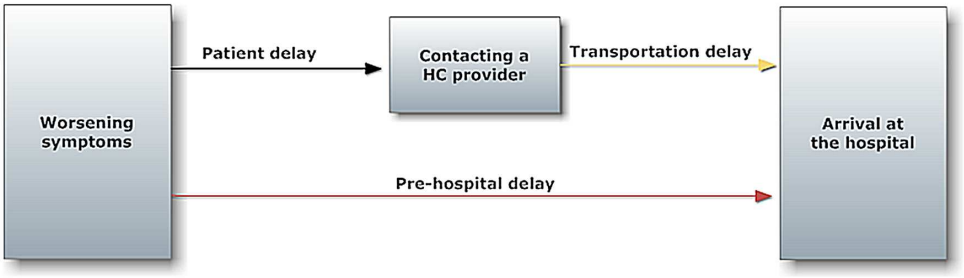


Figure 1. Time schedule of patient-, transportation-, and pre-hospital delay

Male gender, higher levels of HF knowledge, and more HF symptoms were associated with long patient delay.

Self-care behaviour in HF

Self-care behaviour includes compliance with medication, compliance with lifestyle recommendations and symptom management (Figure 2). More insights in factors associated with these components can contribute to further understanding and explanation of self-care behaviour in HF patients.

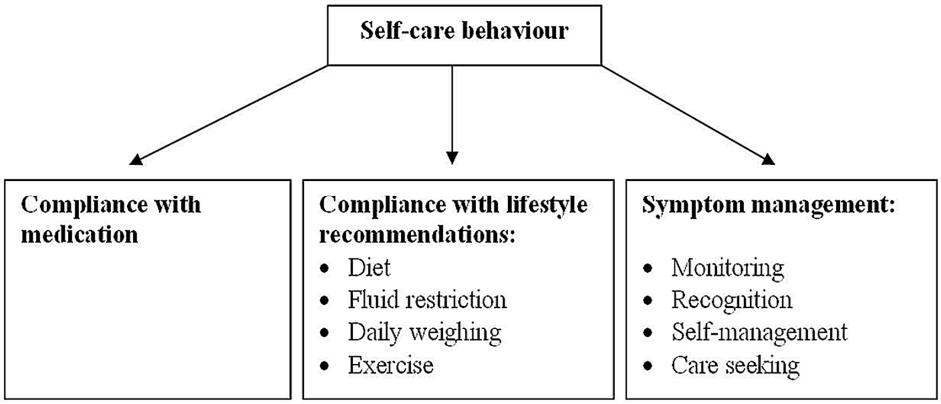


Figure 2. Components of HF-related self-care behaviour

Compliance: Patient-related factors

Patient-related factors can be differentiated into factors that can be changed by education and counselling, and factors that cannot be changed but can be used to identify those patients at higher risk for non-compliance.

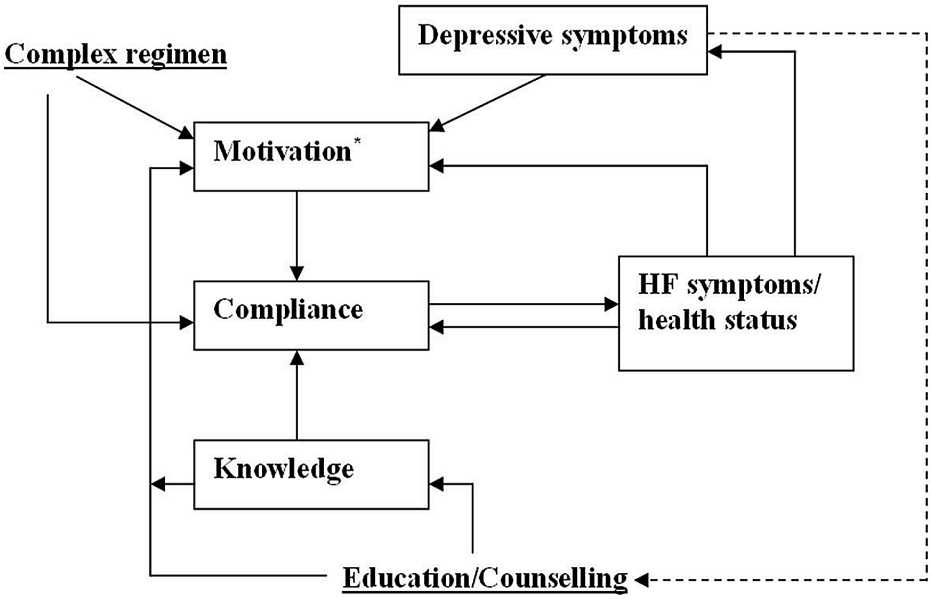
Knowledge is an important factor that is related to compliance in HF patients,[5] and this thesis demonstrates that knowledge is also important in compliance in the long-term. Possibly, knowledge may also play a role in motivation, which was associated with compliance with exercise recommendations; patients who enjoy exercise activity (intrinsic motivation), and those who see it as a tool to obtain beneficial outcome (identified regulation) were more likely to comply. Feelings of guilt or pressure applied by others (i.e. introjected- or external regulation) were not related to compliance.

The Self-Determination Theory[6] distinguishes between different types of motivation and focuses on the degree to which behaviour is self-motivated and self-determined. According to this theory, intrinsic motivation is self-determined, because it refers to doing something because it is inherently interesting or enjoyable. Extrinsic motivation, which refers to doing something because it leads to a separable outcome, can be either self-, or non-self determined. External- and introjected regulation are both non-self-determined aspects of extrinsic motivation, because patients do not experience a sense of choice for engaging in an activity. In contrast, identified regulation reflects the perceived importance of an activity with respect to personal benefits. Due to this value, patients are engaging in an activity out of their own choice and, therefore, identified regulation is self-determined. Therefore, our results indicate that, when patients truly believe that compliance with exercise recommendations will result in favorable outcome (such as better health status), they are more likely to comply, since they are complying out of a self-determined perspective.

Motivation with a self-determined nature (reflecting the patient's own choice to engage in a behaviour) can also play a role in compliance with other recommendations. Beliefs about the HF regimen, consisting of perceived barriers (i.e. potential negative consequences) and benefits (i.e. believed effectiveness), are underlying mechanisms similar to identified regulation when applied to health actions and are found to be associated with compliance.[5] Increasing knowledge on HF and the regimen should provide patients more insight in *how* to perform compliant behaviour and *why* it is important for them to comply with the regimen, with respect to clinical outcome. This can increase motivation in terms of identified regulation. If compliance also actually results in less HF symptoms and better

health status, this will confirm its importance, which should make it easier to maintain compliance.

Patients with depressive symptoms are more often non-compliant,[5,7] possibly due to impaired cognition, feelings of hopelessness or lack of optimism. Given the characteristics of these symptoms, it can be suggested that depressive symptoms will also negatively affect motivation; this may be an underlying mechanism of the relation between depressive symptoms and compliance. Another explanation for this relation is that depressive patients do not seem to benefit from a disease management program directed at education and counselling.[8] Possible pathways of relations between patient-related factors, variables that can affect these factors (regimen-related and health care provider-related factors), and compliance are presented in Figure 3.



*) *Self-determined*

) Depressive symptoms can negatively affect the effectiveness of education and counselling

Figure 3. Pathways of relations between patient-related factors and compliance, and the role of regimen-related (complexity) and health care provider-related factors (education/counselling)

The main conclusion of the results on patient-related factors reflecting increased risk for non-compliance is that it is difficult to identify *the* non-compliant patient, because (1) different variables are associated with non-compliance with different recommendations, and (2) compliance with a particular recommendation does not automatically indicate compliance with other recommendations. This is in contrast with the interpretation of the results of the CHARM (Candesartan in Heart failure: Assessment of Reduction in Mortality and morbidity) study, suggesting that compliance is a marker for compliance with effective treatments other than study medications, or to other behaviours that affect outcome.[1] Although it is plausible that patients, who are compliant and perceive this as important, also find it important to perform other health behaviors (e.g. smoking cessation or avoiding excessive alcohol intake); our study did not support this suggestion. This may be due to the fact that, for instance, smoking cessations requires different 'skills', than engaging in compliance with the HF regimen. It is also possible that patients perceive possible barriers as a result of compliance with the regimen (e.g. thirst, lack of taste in case of low-salted food, practical problems due to the use of diuretics) which may negatively affect the capability to enjoy their life. Consequently, it may be too demanding for these patients to quit smoking or to limit their alcohol intake as well, as this may interfere with the patients' own preferences.

Compliance: Regimen-related factors

This thesis underlines the complexity of the HF regimen and that it is difficult for many HF patients to follow these demanding recommendations. Medication intake should be simplified there were possible: changing the patients' prescription to a 'once a day regimen' is an intervention that could easily be implemented into daily practice and will help patients to manage their complicated HF regimen. In the recent guidelines,[9] less stringent recommendations regarding sodium and fluid intake are formulated, when compared with previous Dutch guidelines[10] used in our own study. Sodium- and fluid restrictions are not evidence based; recent guidelines, therefore, provide nonspecific and less stringent recommendations on sodium- ('Sodium restriction may help control the symptoms and signs of congestion in patients with symptomatic heart failure classes III and IV.') and fluid intake ('Avoid excessive fluid intake: fluid restriction of 1.5-2 L/day *may* be considered in patients with severe heart failure to relieve symptoms and congestion. Routine fluid restriction in all patients with mild to moderate symptoms is probably not of benefit.')[9] It is important that health care providers are adherent to these new guidelines, because these are more easier for patients to follow.

Our studies demonstrated that (long-term) compliance with exercise recommendations is a problem in HF patients. Non-compliance was also found to be the Achilles heel of exercise training programs, such as applied by the Heart Failure: A Controlled Trial Investigating Outcomes of Exercise Training (HF-ACTION) trial.[11] Exercise training can be ideally described in terms of **F**requency, **I**ntensity, **T**ime, and **T**ype (**FITT**).[12] Since only 40% of all patients in the HF-ACTION trial fully complied with the prescribed regimen, the 'FITT' of the program seemed to be too demanding for many HF patients. In our studies, compliance with exercise recommendations was assessed. This may not automatically indicate compliance with an exercise training program, but also with advice on daily physical activity. Unfortunately, from our data it is unknown what specific exercise recommendations patients received from their health care provider. However, physical daily activity should also reach a certain amount of intensity and time, before it will result in physical health benefits. Exercise training may be very difficult to engage in for HF patients with a sedentary lifestyle, due to older age and physical symptoms. These patients should, first, become familiar and comfortable with moderate daily physical activity. Once these patients are activated to become and to remain physically active over a longer period, they may be more eligible to be introduced to activity with higher intensity of even exercise training, as their activity level has been developed gradually.

Compliance: Health care provider-related factors

The studies described in the previous chapters of this thesis were not primary aimed at addressing health care provider-related factors of compliance, in terms of amount of contact with a health care provider. However, in most of these studies, data from the COACH study were used. We found that additional education and counselling by a HF nurse was effective in improving long-term compliance with fluid restriction and daily weighing. Although this is in line with the expectations of COACH, because the interventions were targeted at improving compliance, these interventions had no effect on compliance with medication and exercise recommendations. Considering medication, compliance was very high in patients who received extra education and counselling, but also in patients in the control group. Additionally, in our study on compliance with medication measured by MEMS, also no significant differences in compliance were found between patient in the control group and those in 1 of the 2 intervention groups. However, this can be due to the small sample size of this study. The COACH intervention was not effective in improving compliance with exercise recommendations, indicating that other interventions are needed. Education alone is not effective; health care providers should also address the wide variety of possible

barriers to compliance with exercise and discuss solutions on how to overcome these barriers with their patients, especially in the long-term.[12]

Symptom management

In our studies on delay in seeking care after worsening symptoms, the median patient delay was 48 hours, whereas median pre-hospital delay was 72 hours, indicating that a substantial part of the total delay time consists of time directly related to the patients' own decision. Reported delay in acute coronary syndrome (ACS) is much lower (with most reported median pre-hospital delay times varying from 1.5 to 6 hours).[13] This difference in delay time between HF patients and patients with ACS may be explained by the nature of their symptoms. Because of the acute and threatening nature of worsening ACS symptoms, patients are not able to manage these symptoms themselves and are forced to seek care in an earlier stage. In contrast, worsening HF symptoms can occur gradually and such symptoms may be more eligible for self-management, irrespective of its effect. Some HF patients also wait for a decline in HF symptoms, which is unlikely in ACS. It is known that increased time from worsening ACS symptoms to treatment is associated with increased morbidity and mortality.[13] Although it is suggested that many admissions could have been prevented if HF patients had sought medical care in an earlier stage of worsening HF symptoms, it is still unclear whether or not longer delay in HF will affect outcome with the same magnitude as in ACS. The gradual pattern of worsening HF symptoms results in a wide variety of reported delay times, and it is, therefore, difficult to formulate cutpoints that can differentiate between short and long delay with respect to clinical outcome. Moreover, if patients manage their symptoms adequately, long delay in HF does not always indicate inadequate self-care behaviour.

Ideally, patients should find a balance in when to manage their symptoms themselves and when to seek care. On the one hand, given the fluctuating pattern of HF symptoms, it is not favorable that patients call a health care provider immediately after every change or after even the slightest signs of worsening (Figure 4a). This is one of the explanations of the results of the Diagnostic Outcome Trial in Heart Failure (DOT-HF), a study using an implantable diagnostic tool to measure intrathoracic impedance with an audible patient alert (OptiVol).[14] Patient in the treatment-arm had significantly more outpatient visits, compared with patients in the control group, whereas HF symptoms were similar in the 2 groups. The Optivol threshold used in this study had a high sensitivity, but also at the same time a low specificity, resulting in many unnecessary outpatient visits in the treatment arm. On the other hand, waiting too long with seeking care after worsening

symptoms (specifically in conjunction with inadequate symptom management) can result in dangerous conditions with admissions as a result (Figure 4b). It is also possible that in a certain stage of deterioration, even adequate symptom management will not prevent an admission and that calling a health care provider is the only remaining option.

A history of MI or stroke was associated with short patient delay, suggesting that patients with such history were less likely to take the risk of waiting with seeking medical care when worsening symptoms occur, due to their early experience with a life-threatening event. However, a history of a previous HF admission was not associated with short delay.

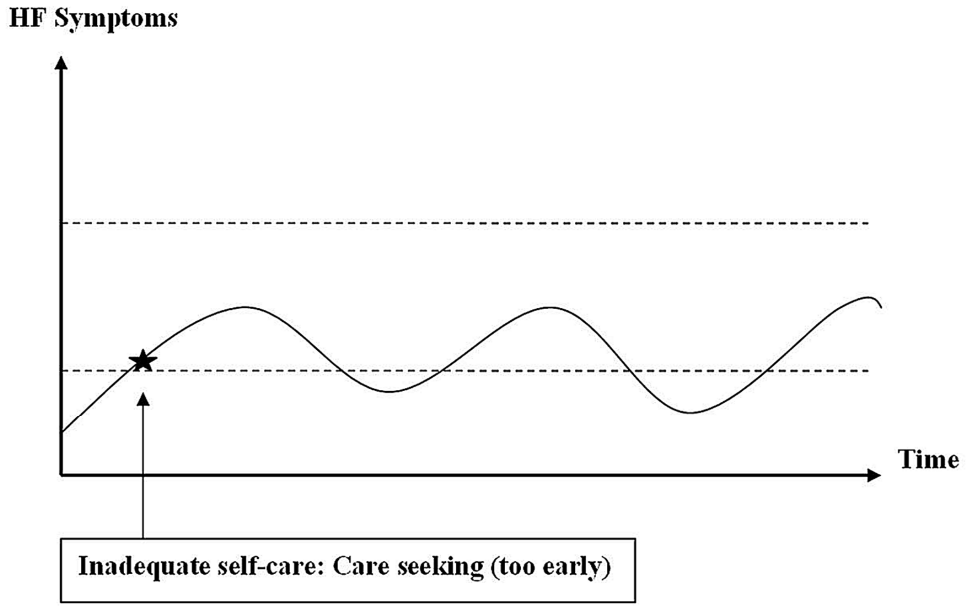


Figure 4a. Inadequate self-care in case of worsening symptoms
This figure illustrates a fluctuating pattern of HF symptoms. The 2 dotted lines reflect an area at which the range of worsening symptoms does not indicate deterioration but represents the natural course of HF. Symptoms will decline automatically, or by adequate self-care behaviours, such as taking extra diuretics or rest. Therefore, patients are too early at this stage in seeking care.

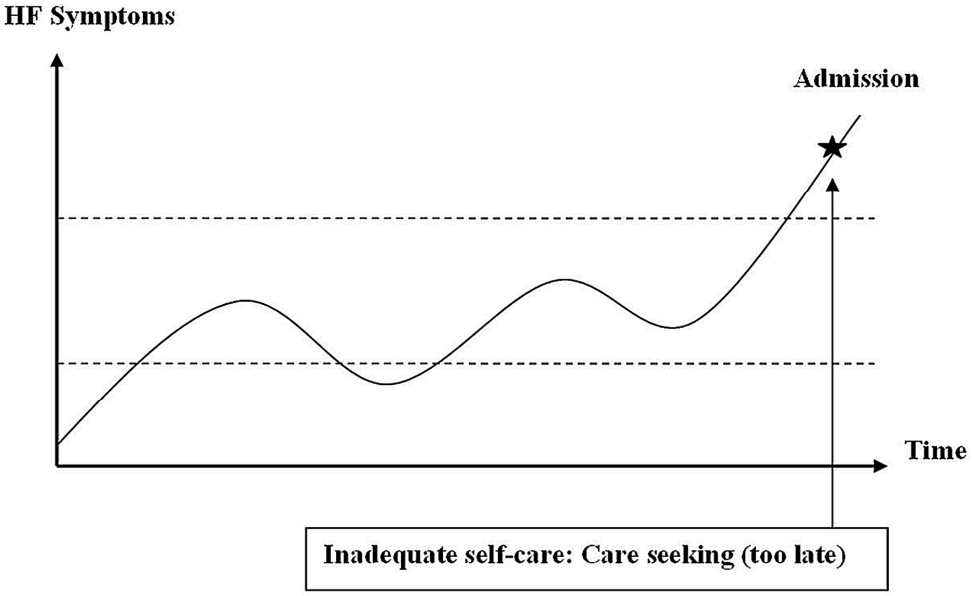


Figure 4b. Inadequate self-care in case of worsening symptoms
This figure also illustrates a fluctuating pattern of HF symptoms. In this case, worsening symptoms are warning signs of further deterioration. Seeking care at this stage is too late and an admission is inevitable.

Possibly, such HF history was not perceived as threatening with the same magnitude as MI or stroke. Therefore, the urgency of 'new' deteriorating HF symptoms may not have been recognized in many patients, suggesting that these patients do not seem to benefit from their previous experience with HF.

The presence of depressive symptoms was associated with longer pre-hospital delay. Maladaptive coping strategies are common in HF patients with depressive symptoms, and from this perspective, it may be unlikely that these patients had managed their symptoms adequately.[15] This suggests that depressive symptoms negatively affect early care seeking, but also adequate self-management, and underlines that depression is a major problem in HF considering self-care behaviour, but also with respect to clinical outcome and quality of life.[5,16,17]

Limitations

In the previous chapters, limitations specific for that particular study were described. In this section, methodological issues of this thesis will be discussed.

To assess self-care behaviour in terms of compliance and delay and its associated variables, several substudies were conducted in the COACH study. COACH was not primary designed to examine self-care behaviour; this may have limited our analyses. We identified variables associated with compliance and delay, however, direction of causality could not have been assessed. Furthermore, in our studies self-care behaviour was assessed by addressing compliance and delay. Self-care behaviour in HF also includes other behaviours, such as smoking cessation, coping or appointment keeping. Therefore, the operationalization of self-care behaviour in this thesis does not fully reflect all aspects of self-care.

Besides MEMS-registration and using a nutrition diary, compliance with the regimen was primarily measured by self-report. It is suggested that self-report is able to detect non-compliance, but may be less sensitive for detecting compliance.[18] Although self-report may be prone to overestimating actual compliance, reported compliance rates with lifestyle recommendations were confirmative with compliance rates reported in other studies. Additionally, reliability of self-reported non-compliance rates has been demonstrated previously.[19] However, in order to obtain data fully reflecting 'true' compliance, objective measurements should be first-choice methods.

Implications for clinical practice

From the studies described in this thesis, several implications for clinical practice can be formulated.

A tailored approach

This thesis underlines the need for a tailored approach in guiding patients to comply with their complex regimen. Health care providers should be aware of the fact that compliance with 1 particular recommendation does not automatically reflect compliance with other recommendations, when they are discussing compliance with their patients. Compliance with each separate recommendation should be addressed and, in case of non-compliance, health care providers should discuss with their patients why they are not complying by addressing barriers, perceived difficulty, or other problems. They should also help patients to implement their prescribed recommendations into their daily lives. In order to make it

less difficult to comply, the complex regimen should be simplified there were possible, dependent on the capability of the individual patient.

Increase knowledge and motivation

Providing information on the importance of compliance with respect to clinical outcome is also crucial when stressing the patients' own active role in their own care and treatment. Recommendations that are easier to follow and perceived as important may result in higher motivation to become and to maintain compliant. This underlines, again, that providing education on the effect of compliance on clinical outcome will motivate patients by increasing identified regulation (i.e. participating in an activity because one believes it is important for personal development or for gaining beneficial outcome) and, subsequently, compliance.

Focus on daily weighing and exercise recommendations

Compliance with daily weighing and exercise was lower than compliance with other recommendations. These recommendations need, therefore, extra attention, especially because non-compliance with daily weighing and exercise is associated with adverse outcomes.[2] Considering daily weighing, health care providers should discuss non-compliance and possible barriers to daily weighing. Furthermore, they should address if daily weighing is indeed necessary, or that a few times per week is also sufficient, or to discuss alternate strategies for checking the body on fluid retention. In order to increase physical activity in HF patients, health care providers should provide education about the importance of physical activity to increase identified regulation. Furthermore, to increase intrinsic motivation, they should discuss what type of physical activity their patients should like to engage in, and to formulate a frequency and intensity of activity, and how physical activity can be incorporated into daily life, tailored to the individual physical condition of the patient.

Symptom management

Patients should also be informed about adequate responses to worsening symptoms. Since longer patient delay will not automatically indicate inadequate self-care behaviour, patients should be educated in what sort of self-care is adequate (e.g. taking extra diuretics) and what is not. Furthermore, patients should be educated about the urgency of seeking care when worsening symptoms continue to persist, despite of performing adequate self-management. At this stage, it is crucial that patients are well informed about who they can

approach for medical help, and that health-care providers (e.g. HF nurse) are easily accessible for them. Health care providers should also evaluate their patients if they are capable to self-manage their symptoms or that they should seek help immediately. Differentiating between patients with first onset of HF and between more experienced patients with a substantial knowledge of HF and the regimen may be a first important step. Patients with a history of HF are possibly more capable in managing their symptoms themselves, and may be more able to interpret the seriousness and status of their symptoms, due to previous experience with symptoms.[20] However, health care providers should keep in mind that a history of HF in terms of symptoms and previous admissions for HF does not ensure adequate self-care behaviour.

Depressive symptoms

Interventions directed at depressive symptoms are important aims in order to increase compliance and may help to reduce delay time. Treating depressive symptoms should also increase quality of life and although little is known on the effect of depressive symptoms on the separate components of motivation described in our study, we assume that depression has a negative effect on motivation in general, given the nature of its symptoms.

Implications for further research

The persistent non-compliant patient

This thesis demonstrates that different variables are associated with compliance with the different aspects of the regimen, indicating that there is no standard profile of *the* non-compliant patient. Nevertheless, although patients do have the required knowledge and recognize the importance of compliance, some of these patients are still not complying with the regimen. This specific population is of major interest and further efforts are needed to identify more characteristics of those patients who do not benefit from providing education and counselling, and to obtain more insights in why they are not complying with the recommendations. This may lead to pathways to the development of interventions targeted at increasing compliance in this vulnerable patient population.

Delay and outcome

The main interest for further research on delay in HF will be to assess how long delay is directly associated with clinical outcome, as is already revealed in the ACS literature. In our study, patient delay was assessed in hospitalized patients; therefore, little is known

whether or not short patient delay may have prevented a (re)admission. By addressing patient delay in patients who were not admitted afterwards, more insight can be obtained regarding long patient delay and outcome in terms of preventing a (re)admission. Furthermore, the long-term consequences of increased delay in HF patients are unknown, and more studies are needed to unravel the underlying mechanisms. Finally, more insight is needed in the patients' own actions and behaviour in the time between worsening symptoms and actually calling a health care provider.

Conclusion

This thesis underlines that adequate self-care behaviour in terms of compliance and delay is still a problem in HF patients, specifically compliance with daily weighing, exercise recommendations, and timely care seeking after worsening symptoms. Since different aspects of the complex HF regimen require different skills from patients, a tailored approach to help patients to manage their complex regimen is stressed, again, to be desirable. However, optimal self-care behaviour (e.g. 100% compliance or 'perfect' symptom management) in *all* HF patients may be an utopia. If patients are truly unwilling or unable to fully comply or to perform 'perfect' symptom management, health care providers and patients should search together for the best possible self-care achievable, which is in line with the non-judgemental approach, formulated by the WHO. The needs and preferences of the individual patient should be incorporated with tailored education and counselling, in order to achieve the most favorable patient-centered approach for 'what the patient wants', but also for 'what the patient needs' with respect to clinical outcome.

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Summary

Summary

Heart failure (HF) is a malignant condition affecting approximately 3% of the general population, with a prevalence of 10-20% in the elderly. Despite improvements in medical care, HF still has a poor prognosis. The complex HF regimen consists of pharmacological treatment and lifestyle recommendations (i.e. a sodium-restricted diet, fluid restriction, symptom monitoring by daily weighing, and maintenance of physical activity).

Adequate self-care behaviour related to heart failure can be defined as 'the actions that patients undertake to maintain healthy functioning and well being', including compliance with medication and lifestyle recommendations, symptom monitoring, self-management of symptoms, and care seeking in case of worsening symptoms. Although compliance, defined as 'the extent to which a person's behaviour coincides with agreed recommendations from a health care provider', positively affects outcomes, many HF patients do not take their medications as prescribed nor do they follow their lifestyle recommendations. Furthermore, long delay times in case of worsening symptoms are common in HF patients. Early recognition of worsening symptoms of HF is important, since these might be warning signs of further deterioration. In such cases, early care seeking might prevent a hospital admission.

Given the evidence for the importance of self-care behaviour, it is a major challenge to identify those patients who are at an increased risk for inadequate self-care behaviour and to assess factors related to inadequate self-care behaviour. Since most of the studies on compliance are cross-sectional, or focus on one specific recommendation only, little is known about long-term compliance with the total package of the separate lifestyle recommendations and its determinants. Also, little is known about the delay time reflecting the patient's own action in seeking care. To obtain more insight in the role patients play in their own care and treatment plan in terms of self-care behaviour and factors related to self-care behaviour, in terms of compliance and delay, the following aims were studied in this thesis:

1) To assess compliance with medication and its associated factors in HF patients.
2) To assess which factors are associated with compliance with lifestyle recommendations in HF patients.
3) To assess long-term compliance with lifestyle recommendations and its associated factors in HF patients.

4) To assess which factors are associated with delay in HF patients after worsening symptoms.

The first part of this thesis addresses compliance with the HF regimen. In chapter 2, differences between self-reported compliance and objectively measured compliance by means of the Medication Event Monitoring System (MEMS) are described. An evidence-based cut point was used to define compliance with medication, which not only reflects (non-)compliance, but also identifies those patients with an increased risk of adverse outcomes. It was found that even though all patients (n = 37) reported 100% compliance, 1 out of 4 patients in fact did not take their medication as prescribed. This indicates that self-report seems to be prone to overestimating the patients' actual compliance. Compared with their compliant counterparts, non-compliant patients more often had a complex medication regimen, had a shorter history of HF, and more often had depressive symptoms.

In chapter 3, objectively measured compliance with a sodium-restricted diet and fluid restriction and its associated variables are examined. Compliance was measured using a nutrition diary and individually prescribed sodium- and fluid restrictions were used to differentiate between compliance and non-compliance. Of all patients (n = 84), 79% were compliant with their prescribed sodium-restriction and 72% with their fluid restriction. Perceived difficulties and the amount of the prescribed restrictions were identified as factors that can negatively affect compliance with sodium and fluid restrictions.

In chapter 4, long-term compliance with lifestyle recommendations (i.e. diet, fluid restriction, daily weighing, and exercise) and its associated variables are assessed in 648 HF patients. Long-term compliance with exercise (range 48%-64%) and daily weighing (34%-85%) proved to be lower than compliance with advice on diet (77%-91%) and fluid restriction (72%-89%). Although knowledge of HF, and education and counselling positively affected compliance with daily weighing and fluid restriction, these were not related to compliance with exercise. Therefore, new approaches are required to increase compliance with exercise. Physical limitations related to older age and comorbidity seem to play a larger role in non-compliance with exercise than physical limitations related to HF itself. These physical limitations should be taken into account when providing exercise recommendations, which in turn should be tailored to the individual patient.

To obtain more insight into compliance with exercise, the role of motivation and perceived control in compliance with these recommendations is assessed in chapter 5. Of all patients (n = 73), 59% reported to comply with exercise recommendations. Higher levels of intrinsic motivation and identified regulation (a component of extrinsic motivation) were

associated with compliance with exercise recommendations, indicating that patients who enjoy exercise (intrinsic motivation) or see it as a tool to obtain beneficial outcomes such as better health status (identified regulation), were more likely to comply with exercise recommendations. Feelings of guilt or pressure applied by others did not seem to affect compliance. Compared with non-compliant patients, compliant patients more often considered regular physical activity to be important and found it less difficult to comply with exercise recommendations. Perceived control was not associated with compliance with exercise.

The second part of this thesis focuses on delay after worsening HF symptoms. The most commonly used definition of delay in the HF literature is *pre-hospital delay*, indicating the time interval between the worsening of symptoms and arrival at the hospital. A substantial part of this pre-hospital delay consists of *patient delay*, defined as the time interval between the worsening of symptoms till the moment of actually contacting a health care provider. In chapter 6, the association between depressive symptoms and pre-hospital delay and its relation between consulting behaviour, measured by means of a validated questionnaire, is assessed, The median pre-hospital delay in this study population (n = 958) was 72 hours. Patients with depressive symptoms were found to have a longer delay from worsening symptoms to hospital admission. Consulting behaviour based on self-report was weakly related to delay, indicating that while some patients report that they plan to seek care in case of worsening symptoms, they do not necessarily translate this into care-seeking behaviour when worsening actually occurs. Consulting behaviour was not correlated to depressive symptoms.

Chapter 7 specifically concentrates on the patient's own role in terms of delay by assessing the specific patient delay and its associated variables. The median patient delay in this study population (n = 911) was 48 hours. Patients with a history of serious, life-threatening events, such as myocardial infarction or stroke, contacted a health care provider earlier in case of worsening HF symptoms, compared with those patients who did not experience such an event. Patients who did not experience a life-threatening event might need to be educated on (the importance of) the recognition and need for appropriate action in a different way than those who have prior experience with a life-threatening event. However, a history of a previous HF admission was not associated with short delay. Possibly, the urgency of 'new' deteriorating HF symptoms may not have been recognised by many patients, suggesting that these patients do not seem to benefit from their previous experience with HF. Male gender, higher levels of HF knowledge, and the experience of more HF symptoms during admission were associated with long patient delay.

In chapter 8 (general discussion), the most important findings of this thesis are summarised and discussed, including implications for clinical practice and further research. This thesis underlines that adequate self-care behaviour in terms of compliance and delay is still a problem in HF patients, specifically compliance with daily weighing, exercise recommendations, and timely care seeking after worsening symptoms. Compliance with 1 recommendation does not ensure compliance with other recommendations, since different aspects of the complex HF regimen require different skills from patients.

For clinical practice, this implies that compliance with each recommendation should be addressed, and, in case of non-compliance, health care providers should address the barriers, perceived difficulties, and other problems patients might experience with respect to their HF regimen. They should also help patients implement the prescribed recommendations into their daily lives. Providing information on the importance of compliance with respect to clinical outcomes is also crucial when stressing the patients' own active role in their care and treatment plan. Additionally, the complex regimen should be simplified where possible: recommendations that are easier to follow and perceived as important may increase motivation to become and to maintain compliant. Extra attention should be paid to compliance with daily weighing and exercise recommendations. Interventions directed at depressive symptoms are important for increasing compliance and improving quality of life, and could also play a role in reducing delay time. With respect to care seeking after worsening symptoms, patients should be informed about adequate responses to worsening symptoms by receiving education on what sort of self-care is adequate (for example, taking extra diuretics) and what is not. In addition, patients should be educated about the urgency of seeking care when, despite having performed adequate self-management, worsening symptoms continue to persist. At this stage it is crucial that patients are well informed about the health-care providers they can approach for medical help. Furthermore, these health-care providers (for example, HF nurses) should also be easily accessible to them.

Further research should be targeted at identifying the characteristics of persistently non-compliant HF patients who do not benefit from education and counselling. Reasons for non-compliance with recommendations should be examined in this specific, and also vulnerable, patient population. Further research on delay in HF should be aimed at gaining a clear insight into patients' own actions and behaviour during the time interval between worsening symptoms and care seeking. Another interest for further research on delay is to assess the relation between long delay and clinical outcome.

Samenvatting

Samenvatting

Hartfalen is een ernstige aandoening die bij ongeveer 3% van de bevolking voorkomt, met een prevalentie van 10-20% bij ouderen. Ondanks verbeteringen in de medische zorg heeft hartfalen nog steeds een slechte prognose. De complexe behandeling van hartfalen bestaat uit het voorschrijven van medicatie en leefregels (natriumarm dieet, vochtbeperking, dagelijks wegen om het lichaam te controleren op vochtretentie, en bewegen).

Bij hartfalen kan adequate zelfzorg gedefinieerd worden als ‘acties die patiënten ondernemen om hun gezondheid en welbevinden te behouden’, inclusief therapietrouw met betrekking tot medicatie en leefregels, het monitoren en zelfmanagement van symptomen, en het inschakelen van medische hulp bij verergering van symptomen. Therapietrouw, gedefinieerd als ‘de mate waarin de patiënt zich houdt aan de adviezen en leefregels’ heeft een gunstig effect op de prognose. Er zijn echter nog steeds veel patiënten met hartfalen die hun medicatie niet innemen zoals voorgeschreven en die zich niet aan de leefregels houden. Veel patiënten wachten lang met het inschakelen van een hulpverlener bij verergering van symptomen van hartfalen. Dit wordt ook wel ‘delay’ genoemd. Vroegtijdige herkenning van deze verergering is belangrijk, omdat dit een waarschuwing kan zijn voor verdere verslechtering. Daarbij kan het vroegtijdig inschakelen van een hulpverlener een ziekenhuisopname wellicht voorkomen.

Gezien het belang van adequate zelfzorg is het een enorme uitdaging om patiënten te identificeren met een verminderde zelfzorg en om te onderzoeken welke factoren hiermee geassocieerd zijn. De studies naar therapietrouw waren cross-sectioneel zijn, of specifiek gericht zijn op 1 bepaalde leefregel. Daarom is er weinig bekend over therapietrouw op lange termijn en welke determinanten die hier mogelijk een rol bij spelen. Tenslotte is er weinig bekend over delay tijd die een directe weergave is van de eigen beslissing van de patiënt. Om meer inzicht te krijgen in de rol van de patiënt zélf in de behandeling met betrekking tot zelfzorg, en om de factoren te identificeren die gerelateerd zijn aan zelfzorg in termen van therapietrouw en delay, staan de volgende onderzoeksvragen centraal in dit proefschrift:

1) Welke factoren zijn geassocieerd met therapietrouw met medicatie bij patiënten met hartfalen?
2) Welke factoren zijn geassocieerd met therapietrouw met leefregels bij patiënten met hartfalen?

3) Welke factoren zijn geassocieerd met therapietrouw gemeten op de lange termijn bij patiënten met hartfalen?
4) Welke factoren zijn geassocieerd met delay na verergering van symptomen bij patiënten met hartfalen?

Het eerste deel van dit proefschrift is gericht op therapietrouw. In hoofdstuk 2 van dit proefschrift wordt het verschil tussen zelfrapportage door patiënten en objectief gemeten therapietrouw met behulp van de Medication Event Monitoring System (MEMS) beschreven. De afkapwaarde die is gebruikt in deze studie om op therapietrouw te definiëren is *evidence-based*; hierdoor geeft deze afkapwaarde niet alleen therapie(on)trouw weer, maar identificeert het ook patiënten met een verhoogde kans op een slechte prognose. Deze studie liet zien dat alle patiënten (n = 37) weliswaar aangaven 100% therapietrouw te zijn, maar dat in feite 1 op de 4 zich niet aan de voorgeschreven medicatie hield. Dit impliceert dat zelfrapportage gevoelig blijkt te zijn voor een overschatting van de daadwerkelijke therapietrouw. Therapieontrouwe patiënten hadden vaker medicatie voorgeschreven gekregen die 2-3 maal daags moest worden ingenomen (in plaats van 1 maal daags). Verder waren therapieontrouwe patiënten minder lang bekend met hartfalen en hadden ze vaker depressieve klachten vergeleken met therapietrouwe patiënten.

In hoofdstuk 3 wordt objectief gemeten therapietrouw met een natriumarm dieet en vochtbeperking en de factoren die hiermee samenhangen beschreven. Therapietrouw werd gemeten met behulp van een dieetdagboek, en de voorgeschreven natrium- en vochtbeperkingen zijn per patiënt gebruikt om een onderscheid te maken tussen therapietrouw en therapieontrouw. Van alle patiënten (n = 84) was 79% therapietrouw met hun voorgeschreven natriumbeperking en 72% met hun voorgeschreven vochtbeperking. Factoren die een negatief effect kunnen hebben op therapietrouw met een natrium- en vochtbeperking bestaan uit de problemen die patiënten ervaren ten aanzien van deze beperkingen en de mate van de voorgeschreven beperkingen.

In hoofdstuk 4 worden therapietrouw op lange termijn met leefregels (natriumarm dieet, vochtbeperking, dagelijks wegen en bewegen) en de hiermee geassocieerde factoren onderzocht in een populatie van 648 patiënten met hartfalen. Therapietrouw op lange termijn met bewegen (range 48%-64%) en dagelijks wegen (34%-85%) was lager vergeleken met therapietrouw met dieet (77%-91%) en vochtbeperking (72%-89%). Hoewel meer kennis over hartfalen, voorlichting, en begeleiding een gunstig effect hadden op therapietrouw met dagelijks wegen en vochtbeperking, hadden deze factoren geen invloed op therapietrouw met bewegen. Dit betekent dat andere benaderingen nodig zijn om

therapietrouw met adviezen over bewegen te verbeteren. Fysieke beperkingen ten gevolge van ouderdom en comorbiditeit bleken een grotere rol te spelen bij therapietrouw met bewegen dan beperkingen ten gevolge van hartfalen. Deze beperkingen moeten in acht genomen worden bij het geven van adviezen 'op maat' over bewegen aan de individuele patiënt.

Om meer inzicht te verkrijgen in therapietrouw met bewegen wordt in hoofdstuk 5 de rol van motivatie en de mate waarin patiënten denken controle te hebben over hun eigen gezondheid bij therapietrouw met bewegen onderzocht. Van alle 73 onderzochte patiënten rapporteerde 59% dat ze therapietrouw waren met de adviezen over bewegen. Een hogere mate van intrinsieke motivatie en *identified regulation* (een component van extrinsieke motivatie) waren geassocieerd met therapietrouw met bewegen. Dit betekent dat patiënten die het leuk vinden om aan beweging te doen (intrinsieke motivatie), of die het zien als een manier om gunstige uitkomsten te verkrijgen zoals een betere gezondheid (*identified regulation*), vaker therapietrouw zijn met bewegen. Gevoelens van schuld of druk opgelegd door anderen bleken geen invloed te hebben op therapietrouw. Therapietrouwe patiënten beschouwden regelmatige lichaamsbeweging vaker als belangrijk en vonden het minder moeilijk om zich aan de adviezen te houden ten opzichte van therapieontrouwe patiënten. De mate waarin patiënten controle denken te hebben over hun gezondheid was niet geassocieerd met therapietrouw.

Het tweede deel van dit proefschrift is gericht op delay na verergering van symptomen van hartfalen. De meest voorkomende definitie van delay is *pre-hospital delay*, welke de tijd weergeeft tussen verergering van symptomen en opname in het ziekenhuis. Een aanzienlijk gedeelte van *pre-hospital delay* bestaat uit *patient delay*, gedefinieerd als de tijd tussen verergering van symptomen en het daadwerkelijk bellen van een hulpverlener. In hoofdstuk 6 is gekeken naar het verband tussen depressieve symptomen and *pre-hospital delay*, en is de relatie met consultatiegedrag gemeten met een vragenlijst. In deze studiepopulatie (n = 958) had de *pre-hospital delay* tijd een mediaan van 72 uur. Uit dit onderzoek kwam naar voren dat patiënten met depressieve symptomen een langere delay hadden tussen verergering van symptomen en ziekenhuisopname. Consultatiegedrag op basis van zelfrapportage was zwak gerelateerd aan delay; dit betekent dat hoewel sommige patiënten aangeven dat ze hulp zullen inschakelen bij verergering van symptomen, ze dit eigenlijk niet doen wanneer verslechtering zich daadwerkelijk voordoet. Consultatiegedrag was niet gecorreleerd met depressieve symptomen.

In hoofdstuk 7 wordt specifiek gefocust op de delay tijd die direct een gevolg is van de beslissing van de patiënt zélf (*patient delay*). De mediane *patient delay* tijd in de

studiepopulatie (n = 911) was 48 uur. Het bleek dat patiënten die al eerder een levensbedreigende ziekte hadden meegemaakt, zoals een hartinfarct of beroerte, eerder een hulpverlener inschakelden bij verergering van symptomen van hartfalen, dan patiënten die geen eerdere ervaringen hadden met deze levensbedreigende ziektes. Patiënten zonder een dergelijke voorgeschiedenis zouden daarom op een andere manier voorgelicht moeten worden over het (belang van) herkennen van een verergering van symptomen en het belang van adequaat handelen, dan patiënten die wel een levensbedreigende ziekte hebben meegemaakt. Een eerdere opname voor hartfalen was echter niet geassocieerd met korte delay. Mogelijk wordt de ernst van verergering van 'nieuwe' symptomen van hartfalen niet herkend door veel patiënten, wat suggereert dat deze patiënten niet geleerd hebben van hun eerdere ervaring met hartfalen. Het mannelijke geslacht, het beschikken over meer kennis over hartfalen, en het ervaren van meerdere symptomen van hartfalen waren geassocieerd met lange *patient delay*.

In hoofdstuk 8 worden de belangrijkste resultaten van dit proefschrift samengevat en besproken, en wordt er aandacht besteed aan de implicaties voor de praktijk en vervolgonderzoek. Met dit proefschrift wordt onderstreept dat adequate zelfzorg, in termen van therapietrouw en delay, nog steeds een probleem is bij patiënten met hartfalen. Dit geldt in het bijzonder voor dagelijks wegen, bewegen en het tijdig inschakelen van medische hulp bij verergering van symptomen. Therapietrouw met één bepaalde leefregel betekent niet automatisch therapietrouw met andere leefregels, omdat verschillende leefregels verschillende vaardigheden van patiënten vragen.

Voor de praktijk betekent dit dat therapietrouw met elke afzonderlijke leefregel besproken zou moeten worden met de patiënt. In geval van therapieontrouw is het van belang dat hulpverleners de redenen hiervoor achterhalen door middel van het uitvragen van barrières, moeilijkheden, en andere problemen die de patiënt mogelijk ervaart. Hulpverleners zouden patiënten tevens moeten helpen om de voorgeschreven leefregels zo goed mogelijk in te passen in het dagelijks leven. Het geven van voorlichting over het belang van therapietrouw met betrekking tot de prognose is ook cruciaal in het kader van het benadrukken van de rol van patiënten zélf in hun eigen zorg en behandeling. Verder zou de complexe behandeling van hartfalen versimpeld moeten worden daar waar mogelijk; leefregels die makkelijker te volgen zijn en die als belangrijk worden gezien, zouden moeten resulteren in een grotere motivatie om therapietrouw te worden, maar ook te blijven. Extra aandacht zou uit moeten gaan naar therapietrouw met dagelijks wegen en bewegen. Interventies toegespitst op depressieve klachten zijn belangrijk bij het verhogen van therapietrouw, kwaliteit van leven, en kunnen een rol spelen bij het verminderen van

delay na verergering van symptomen. In het kader van delay zouden patiënten goed voorgelicht moeten worden over adequate anticipatie op verergering van symptomen, door het aanbieden van educatie over welke zelfzorg adequaat is (bijvoorbeeld het innemen van extra diuretica) en welke niet. Verder is het van belang patiënten voor te lichten over de noodzaak van het inschakelen van een hulpverlener wanneer de symptomen aanhouden of nog meer verergeren, ondanks het uitvoeren van adequate zelfzorg. In dit stadium is het van essentieel belang dat patiënten weten wie zij kunnen benaderen voor medische hulp, en dat de toegang tot hulpverleners (bijvoorbeeld een hartfalenverpleegkundige) laagdrempelig is.

Vervolgonderzoek zou moeten worden toegespitst op het identificeren van karakteristieken van patiënten die therapieontrouw blijven en die geen baat hebben bij voorlichting en begeleiding. Verder zou meer inzicht verkregen moeten worden in redenen waarom deze specifieke, kwetsbare patiëntenpopulatie zich niet aan de voorgeschreven adviezen en leefregels kan houden. De belangrijkste aspecten van vervolgonderzoek naar delay bij hartfalen zijn om een beter beeld te krijgen van het gedrag van de patiënt zelf in de tijd tussen verergering van symptomen en het inschakelen van een hulpverlener en het onderzoeken van de relatie tussen lange delay en prognose.

Dankwoord

Dankwoord

Dit proefschrift is het eindresultaat van een mooi en succesvol promotietraject. Hoewel de ‘harde eindpunten’ in de vorm van artikelen gebundeld in dit proefschrift misschien wel de belangrijkste graadmeters zijn voor een succesvol promotietraject, zijn er toch ook nog vele andere factoren die bijdragen aan deze definitie. Velen hebben hier direct of indirect een belangrijke bijdrage aan geleverd. Hen wil ik hier graag bedanken.

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Curriculum Vitae

Curriculum Vitae

Maurice Mas Wijaja Nieuwenhuis werd geboren op 20 juni 1980, te Jombang (Indonesië). In 1998 behaalde hij zijn gymnasium diploma aan het Dr. Nassau College in Assen. Hierna ging hij psychologie studeren aan de Rijksuniversiteit Groningen, met als afstudeerrichting klinische psychologie. Na een succesvolle afronding van zijn onderzoeksstage op de afdeling van de basiseenheid klinische- en ontwikkelingspsychologie op de faculteit der Gedrags- en Maatschappijwetenschappen (leerstoelgroep 'Experimentele Psychopathologie') behaalde hij in juli 2007 zijn doctoraal diploma. Het onderwerp van zijn onderzoeksstage was aandachtscontrole bij waarneming van affectief geladen materiaal en in het verlengde hiervan was hij nog 1 jaar werkzaam als onderzoeksmedewerker op dezelfde afdeling. In januari 2009 startte hij met zijn promotietraject aan de faculteit der Medische Wetenschappen aan de Rijksuniversiteit Groningen met dit proefschrift als resultaat. Het in dit proefschrift beschreven onderzoek is uitgevoerd op de afdeling cardiologie van het thoraxcentrum van het Universitair Medisch Centrum Groningen.

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